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PATIENTS' USE OF HEALTH INFORMATION FROM THE INTERNET:

EXPLORING THE IMPACT ON PRIMARY CARE

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ABSTRACT

An increasing number of patients actively seek health information from the internet. Patients value the internet for health; however evidence suggests that health professionals perceive it as a challenge to their role. This study aims to investigate patients' use of the internet in primary care and to investigate the association between socio-economic status and internet use.

Patients (n=851) attending two general practices in South Wales were surveyed about use of the internet for health in Phase 1. In Phase 2 interviews were conducted with a sample of these patients (n=50) and practice staff (n=10) to explore their views about patients' use of the internet and its impact on primary care. In the final phase, an on-line discussion forum with relevant stakeholders (n=73) explored views about the current and future role of the internet for patient information.

Patients accessed their doctor significantly more for information about health in comparison to any other source. The internet was also highly valued, with 52% of study participants having used it for health information. Generally, primary care patients used the internet to complement – rather than replace - information received by their doctor.

There were differences amongst patients according to age, gender and socio-economic status in internet access, variety of health information used, and reliance on health professionals. Most health internet users acknowledged that their decision making was more informed and autonomous. A more patient-centred approach to consultations is advocated in the form of partnership with health professionals. This has yet to be realised in primary care, partly due to reluctance by patients and partly due to the current constraints on primary care consultations.

This study shows that the internet is clearly an agent of change, which is shifting the way patients interact with health professionals in primary care. Patients would prefer to use the internet in partnership with health professionals, yet this need is currently not met within a primary care environment. It is important that patients and health professionals receive adequate training in using the internet for health information to make best use of this resource in the future.

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AUTHOR'S DECLARATION

I declare that the work in this thesis was carried out in accordance with the Regulations of the University of Glamorgan/Prifysgol Morgannwg. The work is original except where acknowledged or indicated by special reference in the text. No part of this thesis has been submitted for any other degree.

Any views expressed in the thesis are those of the author and in no way represent those of the University of Glamorgan/Prifysgol Morgannwg.

The dissertation has not been presented to any other University for examination in the United Kingdom or overseas.

SIGNED

DATE

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CHAPTER ONE: INTRODUCTION

THE INTERNET AND THE MODERN PATIENT

1.1 Introduction

> 'The 21st century will be the age of the net empowered user and the patient driven online support networks of today will evolve into more robust and capable guidance systems that will allow end users to direct and control an ever growing portion of their medical care' (Ferguson, 2002, p 555).

This thesis explores patients' use of health information from the internet in primary care. The internet is a modern phenomenon which has revolutionised the way in which information is exchanged in all areas of life, including health care. Patients can now access an unprecedented volume of information about health. They may communicate with doctors through e-mail, talk to other patients globally about their experiences of health and illness or even calculate risk factors by using online risk assessment tools. The increased use of e-health for remote diagnosis through virtual consultations, interactive decision aids and the use of electronic care records illustrate the enormity of the impact of the internet on modern health care. Such uses open up new opportunities for patients wishing to be more involved and learn more about their own health. Consequently, patients may place increasing demands on health services through their interaction with health professionals.

Chapter One outlines patients' use of health information sources, including their preferences and information seeking behaviours. Applications of the internet for health are also introduced. Characteristics of the modern patient are explored by considering how information seeking has influenced the primary care consultation. These issues are contextualized by examining the policy drive towards patient-centred care, and investigating how the use of internet information may impact on such approaches in primary care. A statement of the objectives and scope of the investigation is included, and the chapter concludes with an overview of the structure of this thesis.

1.2 Sources of health information

The majority of people want to be well informed about their health. When a person discovers that they are suffering from an illness, there is an instinctive need to learn more about their condition. Patients frequently seek sources in addition to, or sometimes instead of, the information received from health professionals. Health information is available in abundance, from popular media sources such as magazines, television, radio, newspapers and more recently the internet.

The provision of health information within popular culture is a growing industry. However, more traditional sources such as leaflets are still widely used to provide health information[1]. In the past, the use of leaflets was largely restricted to primary care; however distribution is now far more extensive and includes public areas such as supermarkets. A limitation of written sources is a lack of interactivity, which may cause difficulties for the reader to engage with the material. Telephone-help lines, such as NHS Direct, now offer a more interactive approach by offering patients verbal guidance about the most appropriate course of action. One of the aims of such initiatives was to reduce consultations with health professionals, yet there is currently little evidence to support that this has occurred (Munro *et al.*, 2000).

Informal sources of information such as television, can make a considerable impact on health. This was illustrated by an increase in the uptake of cancer screening (up by 21%) and enquiries to Cancer BACUP helpline, in the period following the death of a TV soap character from cancer (Howe, 2002; Hardyman and Leydon, 2003). Informal or self-care is also an important feature of the community and health service that is often underestimated. Localised support networks such as friends and family are widely used and can have a significant influence on how people care for themselves, or their decision to access health services (Rogers *et al.*, 1998). Self-help groups, in which patients talk to each other to gain support, are also growing in

[1] The introduction of the printing press in the 15th century by Gutenberg provided the first stimulus for patients to consider medical information to address their own needs, rather than relying on their doctor (Coiera, 2003).

popularity. The most well known of these is Alcoholics Anonymous, widely believed to be one of the most effective treatments for alcoholism (Slack, 2001). The essence of self-help groups is that participants can share personal experiences and help each other to recover, or deal with a particular condition.

1.3 Patients' use of health information

Modern society is characterised by consumer choice, much of which is dependent on high quality, accessible information. Traditionally, health professionals have been the main providers of health information, yet recent trends reveal that patients are now choosing to seek supplementary information from other sources (Coulter, 2002). Providing patients with information about health and illness is not new, yet public demand has increased significantly in recent decades. It is difficult to establish why there has been such an increase in the demand for health information. It may be as a result of the rise in interest about health issues, or that information sources are now much more readily available and easily accessible. The increase in leisure time, health promotion and health advertising are also likely to have increased demand.

In the past, information was presented as part of health education campaigns in an attempt to raise awareness about specific issues and encourage healthier lifestyles. These campaigns were often accused of victim blaming as they adopted an individualised, rather than a social model of health. They were highly criticised due to the assumption that the provision of information leads to behaviour change (Lorig and Laurin, 1985). This type of information is unsolicited and so may, or may not, be absorbed by the reader. Attitudes towards health information have been transformed, with more patients requesting information in addition to routine provision. Despite these changes, there is evidence to suggest that patients prioritise their doctor as their preferred and most commonly used source of information (Sparado, 2003).

Patients may access information following a consultation to supplement information provided by a health professional. Alternatively, they may seek information to prepare for a consultation and use it as the basis for future discussions (Malone *et al.*, 2004). Research into patient preferences for information is limited and tends to centre on how effective particular information sources are in providing knowledge, rather than focusing on which sources patients prefer, or whether their needs are met (Wiljer & Catton, 2003). A European survey investigating consumer use of health information from over 16,000 respondents revealed that the majority (45%) reported health care professionals as their main source of health information (Sparado, 2003). Although there is now an extensive range of information available to patients, many still prefer to rely on their doctor and/or nurse for information about health issues.

1.4 Health information on the internet

The popularity and use of the internet is well documented; however, there is less certainty about what patients think of the internet and how they use the information accessed. The internet is a potentially useful resource for patients, as long as they can make sense of, and determine the relevance of the information. Accessing health information on the internet is now one of its most common uses, which continues to increase in popularity (Health on the Net Foundation, 2001). An important concern when considering the provision of information is how accessible it is for patients. We are still a long way from having universal access to the internet. It is therefore necessary to determine which sectors of the population will benefit or be disadvantaged by this development and to consider ways of enhancing access to the internet to bridge the ever increasing digital divide.

The internet is a tool that promotes the free distribution of information (Cahir, 2004). The quality and security of information are important concerns for those accessing information on the internet, yet sufficient regulation of this resource is unlikely in the current climate. Health professionals are in a position to help patients

understand health information by identifying material that is of poor quality or little relevance to the patient. Effective use of the internet is underpinned by a number of factors, firstly adequate access, secondly, the necessary skills to search for information and lastly the ability to understand the information. It is therefore important to further investigate how patients are using the internet and to establish how they can be assisted to make best use of this resource.

The internet offers the ability to have virtual contact with others. In health care, direct patient contact is usually (but not always) considered necessary to provide appropriate treatment. An increase in use of the internet for health could ultimately result in a reduction in face-to-face consultations with health professionals. It is crucial to investigate motivations for use of the internet, to ensure that patients are receiving appropriate care.

1.5 The internet in the context of primary care in the UK

Primary care acts as a gatekeeper to the health services and is responsible for as much as 90% of all health care in the UK (Mihill, 2000). On average, a GP will have as many as 8,000 face-to-face consultations per year (Pendleton *et al.*, 2003). It is at this initial stage that patients are likely to have the greatest uncertainty and unanswered questions about their health problems. Health professionals in primary care are therefore expected to deal with a diverse collection of issues related to health and illness. The consultation is a highly valued aspect of primary care; however there are increasing calls for GPs to relinquish some of their power as it is not necessary for them to see every patient.

Hardey (1998: 89) argues that the internet is a unique medium, which challenges medical dominance and threatens medical autonomy. Such challenges may lead to deprofessionalisation resulting from a de-mystification of medical practitioners and increasing scepticism about health professionals. Internet informed patients have been labelled as having the greatest influence on primary care with general practitioners being bombarded with reams of information from internet informed

patients. Brown (2000) coined the term *Internet Printout Syndrome* (ISP) to describe patients who attend consultations with thick wads that they have printed from the internet.

The internet is now easy to use, accessible and relatively low cost. Patients no longer have to rely on primary care professionals for information, but can interact with all sorts of electronic information via the internet (Powell *et al.,* 2003). Patients may access information sources created for health professionals. Consequently, the patient may be as informed, or even more knowledgeable, than their doctor. This situation may have repercussions for the relationship between patients and health care professionals. In some consultations there could be a shift in power as the health care professional may no longer dominate the discussion and be the most knowledgeable. This shift in power has particular implications for health professionals in primary care, as GPs will not have expert information about all aspects of health care. The internet may therefore be perceived negatively by health professionals who feel confronted by in-depth and specialist information. This response may reflect their personal use and views of the internet. Despite nearly all GPs being connected to NHSnet, this does not guarantee that the internet is being used by primary care staff.

1.6 Health care and information policy

The interests of health care consumers have become an important consideration for health care policy makers. The strategy *Information for Health* was introduced to improve the health of the nation by making good information available for health professionals and patients (Department of Health, 1998a). Much of the strategy focused on using information and communication technology (ICT) to facilitate more efficient exchange of information, for example, online access to services. The quest for high quality patient information therefore persists as a central feature of health policy. In 2002, the Welsh Assembly Government released *Informing Health Care* which aimed to promote the joint working of patients, carers and professionals supported by the latest evidence base (Welsh Assembly Government, 2002a). This

policy promotes the use of a single electronic health record to be held on a secure server. Similarly to *Information for Health*, much of the policy focused on developing the ICT skills of NHS staff. However, there was also an emphasis on patient and carer empowerment which promoted a challenge to paternalism in health care.

More recently, patient-centred care has emerged as a dominant theme in health policy. It was first introduced as part of *The NHS Plan* (Department of Health, 2000), a major driver of health policy during this decade. In comparison to national policies, individual responsibility for health is given greater attention in Welsh policy. This issue was highlighted by Derek Wanless in his *Review of Health and Social Care in Wales* (Wanless, 2003). This review described an acceptance culture in which people believe that they are likely to become ill in the future. This acceptance leads to a passive approach to health, with little emphasis on the prevention of illness and disease. This outlook is supported by morbidity and mortality data in Wales, which shows that the health of people in Wales is poorer than that of their English counterparts (Welsh Office, 1998a).

Global developments in technology have necessitated an increasing ICT policy trend in the health service. In 2002, the Department of Health launched a National IT Strategy (Department of Health, 2002a). This strategy predominantly focused on the use of ICT for communication and transfer of information within the NHS, rather than using technology to provide information about health and illness. The Welsh ICT strategy *Cymru Ar-lein* (National Assembly for Wales, 2001a) committed to providing accessible ICT facilities for everyone in Wales. Clearly, the use of ICT is a central aspect of current government policy.

A recent relevant policy document, *Better Information, Better Choices, Better Health* issued from the Department of Health (2004a) supports the need for a personalised approach to patient information which should be discussed with general practitioners. There is less evidence to suggest how this may be implemented or encouraged in practice. There is also an increasing emphasis on partnerships in care, however the Partnerships in Health Project (Department of Health, 2004b) in England has shown that doctors are reluctant to relinquish their control of the

consultation. The issues of better information for patients, informed choice, self responsibility for health, partnership and patient involvement are all significant policy drivers which support patient-centred approaches to care.

Recent policy drivers appear to promote greater patient involvement in the health service, yet much of this is yet to be realised. The move towards patient-centredness will not transform health service provision over night as it requires an attitude shift from the current central players, namely the government and the medical profession (Salter, 2003).

1.7 From passive to active – the changing role of the patient

Historically, patients have been one of the most neglected elements of the NHS. The development of medicine has advanced to meet the needs of professionals rather than the patient. This emphasis is slowly changing with the modern patient becoming a central feature of health care. As patients become increasingly informed about their health they may no longer wish to take on a traditionally passive role, but may prefer to have an active part in their health care decisions. As a result of this changing role, patients are now being increasingly described as consumers of health care. Post-modern society has witnessed an increase in the number of patients who challenge the authority of the medical profession. This 'reflexivity' encourages patients to question the role of doctors, rather than simply accepting the traditional doctor-patient relationship (Giddens, 1991: 30; Beck, 1994: 33).

Developments in science and technology have resulted in considerable changes to the modern health care system. The public are now more conscious of the deficiencies in medicine. Many patients therefore attempt to minimise these potential vulnerabilities. One way of achieving this is by accessing information about health and disease. An increasing amount of specialist advice is now available, much of which is accessed by patients. The long-standing dominance of the medical professional has since been demystified. The NHS faces particular scrutiny from the press, which focuses on health scandals such as the serial murderer Harold Shipman

and complaints about the clinical work of gynaecologist Rodney Leward. A study of daily newspapers revealed that there were nearly twice as many negative stories in comparison to positive stories (Ali *et al.*, 2001). Even greater pressure has resulted from public access to information such as health trust league tables and performance targets. Although it is not always possible to exercise choice, or preferences for health care, access to this information makes the patient a more important consumer of the health service.

Following the Bristol Inquiry into the excess death rate in children undergoing heart surgery (Bristol Royal Infirmary Enquiry, 2001), patient-centred care became a central feature of NHS and government policy. The Department of Health promotes patient-centred care, yet there is little clarification about the characteristics of this concept. Stewart *et al.* (2001) contend that to be patient-centred:

> *'...the practitioner must be able to empower the patient, share the power in the relationship, and this means renouncing control which has traditionally been in the hands of the professional'* (p 7).

During the last decade a diverse range of definitions are widely used in the literature, which include patient involvement; the need to share information and decision making; communication and enhancement of the doctor-patient relationship. Patient access to, and use of information about health, is also an increasingly common feature of patient-centred care.

It has been demonstrated that patients welcome patient-centred care, which can facilitate higher levels of satisfaction and promote increased patient outcomes (Little, 2001). Patient-centeredness highlights the need for high quality information for the patient so that they can be more involved in decision making. It is important that information is shared in order to have an understanding of the patient's world (Gillespie *et al.*, 2004). Health professionals can assist patients in their use of health information; however this is not necessarily welcomed in practice (Malone *et al.*, 2004). Patient-centred care can be criticised as it is often presented at an

organisational rather than an individual level which defeats the underlying principles of this approach.

1.8 Aim of study

So far, this chapter has outlined current trends in patient information seeking on health issues. It has been shown that use of the internet by patients has the potential to promote patient-centredness by facilitating a more active role in the management of their health. This descriptive study therefore aims to investigate patients' use of the internet in primary care and will be addressed through the following research objectives to:

- Consider the ways in which patients use health information;
- Examine the impact of socio-economic status on the use of health information sources, including the internet;
- Investigate the role of the internet as an information source;
- Explore patient and professional views about internet information in primary care consultations;
- Provide national and international perspectives on the use of the internet in primary care.

1.9 Definition of terms

The following definitions provide clarification of the primary terminology used in this thesis. A more detailed account of these terms is offered in Chapter Two.

Consumer health information – information that enables individuals to make informed decisions about their health.

E-health – study of information and communication systems in health care.

Internet – a network of computers. Often described as a global computer network that can be publicly accessed. The world wide web (WWW) is a hypertext document system set up for use on the internet.

Primary care – health care provided and accessed in community settings.

Patient-centred care – holistic approach to health care that is responsive to patients' wants, needs and preferences.[2]

1.10 Study overview

This study has used a variety of research methods to address the research question. The research design and methodological issues related to the selection of data collection tools are examined in more detail in Chapter Three. The research project was divided into three distinct phases, each addressing particular aspects of the research objectives. This design provided an opportunity to establish current use of information sources for health, followed by a more detailed investigation of the perceptions and potential implications internet use by patients in primary care.

The location of the research in Wales provided a case study to investigate patients' use of the internet for health information. In general, Welsh patients and professionals are similar to their English counterparts and therefore provide a British context. Primary care was selected as the area of investigation as this is the first point of contact for patients and is commonly used to discuss health information. In addition, the role of the generalist practitioner in dealing with highly specialised information produced by patients was of particular interest. A more in-depth explanation of the study setting is included in Chapter Three (pp 59-93).

[2] This definition is adapted from Laine and Davidoff (1996)

1.11 Structure of thesis

This chapter has provided an overview of the ways in which the internet may impact on the modern patient and more broadly the health service in the UK. Patients' use of the internet and other information sources has been presented. It is contended that patient use of the internet may reinforce the principles of patient-centred care; however it is questioned whether health professionals are fully prepared to embrace the more informed patient.

Chapter Two provides a review of the literature in the field of consumer e-health. Consideration is given to the changing role of the patient and the impact that the more informed patient may have on the relationship between the patient and health professional. A detailed appraisal of patients' use of health information sources is included. Use of the internet is explored as an emerging resource for patients and more broadly medicine as a whole. This chapter is presented in a framework of patient-centredness in primary care. Areas that need further exploration are highlighted, offering a full justification for the current research study.

Chapter Three provides a comprehensive account of the research design adopted for this study. The methods chapter includes a full examination of the scientific principles on which the research design is based. Each of the data collection tools is explained, with particular emphasis on the design and implementation strategies employed. The validity of the data collection and analysis tools are explored to provide a suitable justification for their selection at each phase of the study. The methodological considerations and practicalities of using a novel approach to data collection are examined. The ethical considerations of this study design and execution are also presented.

Chapters Four to Six report the findings from each phase of the study. Chapter Four presents the findings from the patient survey which are illustrated in appropriate tables and charts. Chapter Five presents the findings from the interviews with patients and health professionals and includes verbatim quotes to

illustrate the main themes of the interviews. Chapter Six presents data on the use of the online forum and the main issues raised in these discussions.

Chapter Seven brings together the findings in a discussion chapter. This chapter highlights how the aims and objectives identified in this introductory chapter have been met by the work presented in the thesis. This discussion offers explanations for the research findings, which are placed in context of the literature offered in Chapter Two.

Conclusions and recommendations from this thesis are presented in Chapter Eight. This chapter includes a discussion of the methodological issues raised in this study. Chapter Eight concludes by considering both the implications of the contribution to knowledge presented by this thesis and the future prospects for work in this field.

CHAPTER TWO

THE INTERNET, HEALTH AND PATIENT-CENTRED CARE

2.1 Introduction

There have been considerable changes in the delivery of modern health care. The rise in health consumerism, challenges to medical dominance, innovations in technology and more informed patients have all contributed to these changes. Patients now have higher expectations about their health services, are keen to be more informed about their health and increasingly share decision making about their treatment and care. Sources of information such as the internet have gained increasing popularity within the health service, not only as a way of providing information but also as a method of communication. The internet has many attractions for patients, such as the ability to access a diverse range of information for use in managing their health. To date, the experiences of patients' use of the internet for health have been relatively unexplored.

This review of the literature firstly considers the modern patient in the context of recent health policy in the UK. The role of the internet as an information source is then discussed in relation to its potential application in managing the health information needs of patients. In the second half of the chapter, current medical practice is examined with a particular emphasis on the changing relationship between the doctor and patient. The position of the internet informed patient is explored within the primary care context, specifically in relation to the primary care consultation. This chapter concludes by considering the relationship between health information and patient-centredness in primary care.

2.1.1 Literature search

Initially, a broad literature review was conducted to establish the extent of research in the topic area. Ultimately, the review aimed to summarise the literature to reveal the current state of knowledge, and to demonstrate the relationship between the researcher's intended work and previous research. This review was used to refine the original aims and objectives of the project (p 11). During the last decade, much of the literature has focused on use of the internet by health professionals and the

quality of the health information available on the internet (Pandolfini and Bonati, 2002). The review identified a gap in the literature with respect to patient perspectives on using the internet for health information.

Electronic searches were conducted using CINAHL (Cumulative Index to Nursing and Allied Health Literature - 1990-2005), Medline (1990-2005), Embase (1990-2005) and the Cochrane Library. Initial searches ranged from 1990-2001 but this scope was extended throughout the study to gain the most up to date material as the research progressed. A variety of key words were entered into the above-named databases:

Table 2.1: Searching strategy using key words

Key term	**Combinations**
Internet	World-wide web, electronic information, computers, IT/ICT.
Health information sources	Patient information, leaflets, media, magazines, newspapers, TV, books, help-lines, journals.
e-health	Computerized information, health informatics, health communication.
Consumer	Patient, client, user.
Health care policy	Policy, government.
Patient-centred care	Autonomy, patient choice, empowerment, patient involvement, shared decision making.
Primary care	General practice, health professionals, doctors, nurses, community care.
Doctor-patient relationship/ interaction	Consultations, communication.
Online discussion forums (research)	E-forums, bulletin boards, online groups, computer mediated communication, e-moderator.

In total, 3856 citations were screened from the electronic searches and 1217 abstracts were reviewed. Full text articles were obtained and assessed according to methodological quality, source, currency and relevance to the research questions (Clarke & Oxman, 2002). The source of the literature was examined to determine whether the article was peer reviewed and if the study setting was relevant to the project objectives. The methodological quality of the articles was critiqued according to the use of appropriate research methods, sampling and data analysis. The most up to date literature was included in the review; however seminal references were included where appropriate. Selected journals such as, the *Journal of Medical Internet Research*, *British Medical Journal* and *Social Science and Medicine* were consulted frequently as they were of particular relevance to the issues in this study. Bibliographies and references from articles gained from each of the searching strategies were screened using a snow-balling technique to identify additional information sources. A total of 623 full text articles were obtained and 165 were included in the review.

In addition to electronic searches, unpublished data in the form of reports and theses were obtained from professionals and academics working in the field. Relevant policy documents were accessed from local and national government agencies on a regular basis to inform this study. Information was also accessed from discussion lists/fora on the internet (such as consumer-health-informatics@JISCMAIL.ac.uk and bmis-members@yahoogroups.com) and traditional media sources such as newspapers. These sources provided useful and up to date information in such a fast-moving field. Attendance at conferences and author publications provided an opportunity to disseminate findings from the study and promote interaction with key researchers in the field (details are provided in Appendix 1).

2.2 The modern patient

We now live in a society which is far more health conscious than in the past. An increasing number of patients choose to adopt an active role in managing their health by becoming more involved in decisions about treatment and care (Mears and Sweeney, 2000). Traditionally, patients have been viewed in a passive way with an expectation that a sick person will seek professional advice and adhere to treatments in order to get well (Parsons, 1951: 437). However, in recent decades, patient participation in health care has rapidly increased with 'health consumers' supporting the drive for more public information about health care. Coulter (2002) describes the multi-faceted role of the modern patient:

> 'In the 21st century the patient is the decision-maker, care manager, and co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision makers' (p 6).

Patients are now generally more informed and aware of the services available to them; many therefore, strive for greater choice and participation in managing their health.

It could be argued that some patients in the UK are more involved in their health due to a loss of confidence in the NHS. It is widely acknowledged that the provision of information can benefit patients. For example, information can reduce stress levels and anxiety which may result in greater health gains (Fitzpatrick *et al.*, 1983; Garretson, 2004) The introductory chapter highlighted a range of information sources that are now available to patients (p 3). These sources are employed in diverse ways. For example, some patients may access information to gain a greater insight into a newly diagnosed condition, while others may be seeking a second opinion. Recent health care policy in the UK has reinforced the drive towards modernising the role of the patient, by supporting the need for appropriate health information to assist patients in better managing their health. Without appropriate health information, decision-making will not be fully informed, involvement in care management will be constrained and the role of the active citizen will not be fully

realised. Other barriers to informed choice include time, resources, skills, and the absence of continuity of care. Clearly, information can be a powerful resource for health care, yet current provision may not meet patient needs.

2.2.1 The knowledgeable patient

Ten years ago the provision of patient information was described as a 'growth industry' (Meredith, 1995). However, the last decade has witnessed an information explosion which includes interactive developments in technology such as the internet. Despite the availability of many information sources, survey data from Europe and the United States indicates that health professionals persist as the most popular resource for health information (Pennbridge *et al.*, 1999; Sparado, 2003; Cohall *et al.*, 2004; Cotten and Gupta, 2004), and patients continue to rely on health professionals to meet their health information needs.

Popular culture sources such as magazines, television and newspapers, all now contain frequent references to health in the context of life-styles and new methods of diagnosis and treatment. The research literature predominantly focuses on health information sources used by certain patient groups. This literature also provides an international perspective on health information needs. In one UK review, Rees and Bath (2000) concluded that with regard to the information needs of women with breast cancer, patients preferred verbal information from health professionals, but were often dissatisfied with this information. In a survey of Californian consumers (n=1007), Pennbridge *et al.* (1999) found that telephone advice lines, employee assistance programmes, advice books, the internet and health fairs were all used to access health information. Access to health care services is not freely available in the United States in the same way that it is in countries with national health systems, and so their health information seeking behaviour may differ from UK consumers. Jones *et al.* (2001a) investigated the use of health information sources by a representative sample of Spanish primary care patients (n=180). They found that the most frequently used sources were family/friends and the doctor. However, there were marked differences according to age and gender. For example, women were far

more likely to rely on family and friends than men. Clearly, patients may go about seeking health information in different ways. However, research into patient preferences for information is currently limited and tends to focus on how effective sources are in providing patients with knowledge rather than focusing on which sources they prefer or whether their needs are being met.

One concern about the information available to patients is that they are rarely consulted about their preferences or perceived needs when resources are being developed. In order to address such concerns, Coulter (1998) conducted a large scale study which evaluated patient information for ten common conditions/treatments. Patients took part in focus groups, and clinicians used a structured checklist to review 54 different patient information materials. The results showed that patients wanted information which was well-balanced. Many patients considered existing health information as too basic with a tendency to promote a paternalistic attitude. Health professionals my therefore underestimate the role of the patient in determining and fulfilling their health information needs.

2.2.2 The quest for information – proactive or reactive?

Health information is accessed in different ways at different times and can be underpinned by diverse motivations and needs. Some patients may actively seek information by adopting a proactive approach, for example, resulting from a new diagnosis. This type of searching is predominantly for information about specific conditions and has a direct focus. Alternatively, patients may not search for information, but encounter it passively in their everyday activities, for example by reading the newspaper. This type of information covers a range of health issues often targeting more general health and lifestyles.

Health information seeking behaviour can be explained by the beliefs and ideals people have about their health. Rotter (1966) associates such feelings with a locus of control that an individual has over significant events. A person with an internal locus controls their own destiny, whereas those with an external locus of control

leave their destiny to external factors such as fate. Internal controllers are more likely to engage in health information seeking by adopting an active approach to their health. In contrast, an external controller will be more passive, having little or no desire to influence their health by seeking information. Similarly, Miller (1987) in her work about 'monitors and blunters', investigates how individuals seek information in times of stress. In this scenario, personality affects information seeking behaviour. Monitors seek information to cope with stress, whereas blunters avoid information. This interpretation has considerable implications for patients who may be ignoring or avoiding health concerns for fear of finding out what may be wrong with them and forms a large part of the health psychology literature. Those in the economically disadvantaged sectors of society are more likely to have an external locus of control concerning their own health (Pirisi, 2000). An objective of this research is to examine the differences in access and use of health information within relatively deprived and affluent areas to identify potential inequalities in the use of the health internet.

Research focused on particular patient groups provides useful case studies when examining dimensions of health information seeking. For instance, cancer patients have an expressed need for extensive health information. In a small scale survey, Raupauch and Hillier (2002) revealed that nearly all cancer patients (94%, n=217) felt it was moderately or extremely important to have health information on specific issues. However, less than a third had received information about cancer issues during the previous six months. Raupauch and Hillier (2002) found a distinction between information provision and support. Some resources that patients use are provided routinely, whereas far more are based on requests for information. The amount of information required by cancer patients is sometimes underestimated, often as health professionals have made assumptions about what patients want. Fox and Kilvert (2003) refer to the intense education required in order to inform diabetes patients. This is a clear example of where the needs of patients may not be met as there are deficiencies in providing information to educate patients about their condition. Information is often written from the perspective of the medical profession, based on what they feel patients need, rather than from gaining a patient perspective (Coulter, 1998). Although it is logical to focus on the information needs

of patients with specific illnesses, further research is needed into more general health information seeking behaviour and information use.

2.3 Trends in health care policy

Information technology and consumer e-health are integral parts of the modern concept of public health and national health care policies (Eysenbach, 2000a). The UK government is committed to improving public participation in health care and enhancing shared decision making, so that there is more equal partnership between patients and professionals (Kendall, 2001). A review of health policy illustrates that the government is committed to patient involvement in the health service (See appendix 2 for a policy timeline). In a public consultation about the NHS Plan, patients rated '*more prevention - better help and information on healthy living*' as one of the top ten most important elements that they wanted to see in the NHS (Patients' Voice, 2000). In support of this objective, the government has set up a 'national knowledge service' (http://nelh.nhs.uk/nks-wwwroot/default.asp) which aims to integrate existing sources of health information so that patients can be made aware of high quality information. It is clear that patients want access to more user-friendly information and that policy makers intend to support these needs.

Health information plays a central role in the policy agenda, primarily to ensure that patients are fully informed about their health and the availability of current health service provision. A key objective of *Information for Health* (Department of Health, 1998a) focussed on the value of quality information:

> 'To provide fast, convenient access for the public to accredited multimedia advice on lifestyle and health, and information to support public involvement in, and understanding of, local and national health service development' (p 3).

Similar objectives have emerged throughout subsequent health policy development, outlining the contribution that appropriate health information can make to public awareness about health (Welsh Office, 1998b; Department of Health, 2001a; Welsh

Assembly Government, 2002a; Department of Health, 2003; Department of Health, 2004a; Department of Health, 2004b). The limitations of existing information are acknowledged, particularly the *'bewildering amount of information available to the public...of questionable quality'* (Welsh Office, 1998c). However, on closer inspection, many of these strategies target the technological aspects of the information infrastructure, such as electronic health/patient records and online bookings. Early policy documents focus more on the use of information by health professionals; less emphasis is placed on providing information for patients.

The rhetoric of policy is rarely realised in reality. This concern was acknowledged in *Implementing Information for Health*, a policy document which called for information agencies to work in harmony to make realistic progress (Department of Health, 2002b). One of the largest strategies was the National IT programme (Department of Health, 2002a) comprising an investment of £6.2 billion to revolutionise the organisation of information in the NHS. This programme, spanning over 10 years, aims to link general practice, acute and community settings through a secure system which will include a basic electronic health record for all patients and has introduced some of the biggest computer systems available. This programme was necessary in order to provide an infrastructure for expanding telemedicine and the introduction of electronic medicine. However, progress with the strategy has been slow and plagued by embarrassing ICT fiascos, such as the crash of the new e-mail system introduced in 2004. There are also concerns about the secrecy of the project and that clinicians have not been suitably consulted about the IT strategy, despite having a key role in its implementation (Humber, 2004). Furthermore, less attention has been given to patients' use of ICT. Given these early setbacks it would suggest that a more robust approach is needed for unregulated sources of health information such as the internet.

2.3.1 Clinical governance

It was only in the late 1980s that consumer groups began to have a real impact on the policy agenda. Although consumer health groups were in existence prior to this, they were subject to medical pressure, adopting a passive stance. Haywood and Hunter (1982) describe an 'iron-triangle' comprising the medical profession, ministers, and officials who would resolve any differences through formal and informal networks. This relationship was embedded in the belief that the medical profession holds power and control over scientific knowledge and therefore dominates the doctor-patient relationship. An orthodox approach to medicine ensures that the profession holds both medical and economic power where the role of the patient is characterised by their need for health care. Klein (1989) describes the foundation of the NHS as an agreement between the government and the medical profession, that the government controls health service funding, but the medical professional are responsible for how it is distributed. There was an inherent assumption that doctors work clinically in the interests of the patient and so there was no need to question these principles. Although the increased power of the patient has facilitated some of these changes, there is still a belief that they can only have a limited influence on the medical profession (Wood, 2000).

There has been a considerable increase in the regulation of the medical profession following events such as those at the Bristol Royal Infirmary Inquiry (Bristol Royal Infirmary Enquiry, 2001). In addition to more formal inquiries, the media, consumer groups, individual patient and their families have also influenced regulation in the health service. Self-regulation of medicine still dominates, however attempts have been made to put the medical profession under greater scrutiny by introducing clinical governance to monitor standards (Department of Health, 1998b). A host of governing bodies now exist to maintain clinical standards including the National Institute for Clinical Excellence (NICE), National Service Frameworks (NSF) and the National Clinical Assessment Authority (NCAA) to name a few (Department of Health, 2001b; Department of Health 2001c). Despite attempts at regulation, much of the accountability of doctors lies within the jurisdiction of other doctors, not with

patients. Gray (2002) offers a defensive response to regulation, claiming that government policy is deprofessionalising doctors, who are *'under unprecedented attack through these government proposals'* (p 628). Given that these initiatives question the power of doctors, less attention has been given to how increasing regulation is perceived and implemented by the medical profession.

2.3.2 Patient-centred policy

A proliferation of recent policy documents place the patient as the key player in the health service (Welsh Office, 1998c; Department of Health, 2000; National Assembly for Wales, 2001b; Department of Health, 2001d; Welsh Assembly Government, 2002a; Welsh Assembly Government, 2002b; Wanless, 2003, Department of Health, 2004c). The government is encouraging patients to take more responsibility for their health claiming that, *'The NHS has to be redesigned around the needs of the patient'* (Department of Health, 2000, p 11). Public involvement is a major theme to improving health in Wales with an individualised approach to care. The retention of Community Health Councils (CHCs) in Wales signifies the commitment to encouraging public involvement in health service planning (National Assembly for Wales, 2001b). A review of Health and Social Care in Wales calls for a, *'step-change in individual's and communities' acceptance of responsibility for their health'* (Wanless, 2003, p 2). The policy drive is supported by the need to raise public awareness about the evidence base associated with health behaviours. An increased awareness could be achieved through, *'better use of the media and other means of communication to inform and motivate people to look after and to improve their health'* (Wanless, 2003, p 54). The review signified a more realistic vision about the impact of such changes, proposing a patient-centred service in twenty years time.

Partnerships in care have also been widely supported, with the aim of patients, carers and professionals working together by discussing the latest evidence (National Assembly for Wales, 2001b; Department of Health, 2003; Department of Health 2004b). Shared decision making is a long term initiative but interim steps should be taken by providing better information (Elwyn *et al.*, 2000). An example of

partnership is displayed in the 'Expert Patient' Programme (EPP) in England, which provides a self-management and self-care programme for people living with long term conditions (Department of Health, 2001d). In August 2004, the EPP delivered 1,100 courses that were attended by 12,000 people (Expert Patients Programme, 2004). This programme is clearly embraced by patients, yet there is less enthusiasm from health professionals who envisage an increase in time to consult with a more informed and demanding patient (MORI, 2003). Ironically, the expert patient is a programme that is built on partnership where the patient contributes their experiences of the disease in conjunction with medical expertise. The term 'expert' has been criticised as it could trigger a sense of hostility. A more favoured term is the 'involved patient', which promotes a sense of partnership (Shaw and Baker, 2004). It could be suggested that we are currently experiencing policy overload, however the attempt to give greater importance to the role of the patient is a positive trend. It is important to focus on good strategies for communication and joint working between patients and health professionals to realise the full potential of these strategies.

2.4 The internet – a new information age

In recent years there have been significant advances in information technology. The internet has had a considerable impact on how people exchange information. The internet can be traced back to the 1960s to an internal computer network devised by the United States Department of Defence to send government information between various agencies (Slack, 2001: 69).[1] Subsequently, the private sector also created their own networks which developed into what we commonly know today as Internet Service Providers (ISPs). The world-wide web emerged in the early 1990s, which coupled with the introduction of web browsers, began to attract an escalating

[1] The Advanced Research Project Agency Network (ARPNET) was mainly used to send large files of information. In the 1980s the National Science Foundation (formerly the Defence Department) sponsored a national network of computers which was later to be known as the internet. This was used to connect smaller networks of computers from a variety of sectors such as the government, industry and academia. This greatly improved the speed and efficiency of communication.

number of users (Joinson, 2003). Eventually, access was also available for the personal user if they had access to a home PC, phone-line and modem.

Internet technology has progressed rapidly from the initial use of dial-up access, through the use of a modem, to broadband services which offer a much quicker and efficient form of access. The internet is now also used on platforms such as mobile-telephones, digital television and games consoles. The UK government has invested in digital television services (DTV) and pledged to remove analogue services in the next five years. Despite such initiatives, uptake of the internet via other platforms, such as digital TV has been low (Selwyn *et al.,* 2005), yet this resource has the potential to offer more than fixed web pages. An evaluation of a pilot of the health applications of digital TV revealed a market for this type of provision, however further consideration must be given to the format of health services on TV (Department of Health, 2002c).

The internet has become an increasingly popular resource for consumers. It is no longer merely a source of information or communication, but offers a means for consumers to conduct a variety of activities. E-mailing is still one of the most common uses of the internet; a recent survey found that about half of consumers now actively use the internet to order tickets, goods or services (Office for National Statistics {ONS}, 2003). E-mail is the most popular activity for Welsh consumers with 68% (n=758) citing e-mail as the most frequent use in 2003. However, only 36% (n =410) used the internet to order tickets, goods or services, much lower than the national average (Welsh Consumer Council, 2003). In recent years, consumer use of the internet for commercial reasons has gained increasing popularity, for example, purchasing/selling goods on *e-Bay*, online gambling and buying pharmaceuticals. The internet has a range of potential uses for those with the ability to access this resource, yet many sectors of society are still unable to experience it or do not wish to rely on it.

2.4.1 The digital divide

The 'digital divide' is a term used to describe the disparity between those with access to digital technology and those without. As developments in information technology reach new and higher levels, the divide also increases between those who are able to use such technologies and those who can not. Although computers have been commonplace in society for decades, the introduction of personal computers and the internet at home have revolutionised access to information for the consumer. Internet access is increasingly being made easier in terms of the technology available and the associated costs. Yet there are still many sectors of society who do not have access to this potentially valuable source of information. A report of internet and IT use in the European Community refers to an 'offline underclass' as 28% of Europeans do not own a PC, digital television, games console or mobile phone (Holbey, 2001). The digital divide is associated with many factors such as age, gender, education, employment, regional and global differences. It is important to consider whether electronic sources such as the internet are a worthwhile source for consumers, in order to determine whether those without access will be disadvantaged. One objective of this study is to investigate whether the digital divide is evident in South Wales, firstly, in relation to access to the internet and secondly, in the ways people use it.

The provision of free public access to the internet is one way of challenging the digital divide. Government schemes have been introduced to provide free computers and free access to the internet in all UK public libraries. However, those without internet access at home are also less likely to use public access points. Non-use may occur as those without home access do not have sufficient ICT skills and so the issue is more than just accessibility, it also concerns proficiency and confidence. Attempts have also been made to improve access to technology among lower socio-economic groups. For example, the UK government pledged that all schools would be connected to the internet by 2002, over 100,000 of the poorest families would receive subsidised computers and 800 ICT learning centres would be established (Blair, 1999). Part of these initiatives provided computer loan schemes

to people who did not have a computer at home. Although these schemes have been generally well received, the digital divide is still apparent today, some three years on from the initial target uptake. The government has also been heavily criticised for having an 'overly simplistic' view of the technology (Hudson, 2002).

Although some of the common reasons for non-use of the internet include lack of interest or skills to use the internet it is often assumed that financial cost is the greatest barrier to internet access. Cost however only deters about 1 in eight (12%) people from using the internet (Welsh Consumer Council, 2003). Some non-users simply do not feel the need to use the internet, while others actively avoid it and have no desire to use it in the future (Potts & Wyatt, 2002; ONS, 2005a). Some of the reasons for non-use are clearly not due to difficulties accessing the internet, but are determined by social factors. It is therefore necessary to consider the factors that influence use and non-use of the internet in more detail, rather than focussing merely on access and usage rates. Seemingly, many people are making the choice not to use the internet as an information source. It is important that this freedom of choice should be maintained; however, a greater concern is whether this choice is informed, in the sense that consumers are aware of the potential uses of the internet and the associated risks and benefits.

Welsh consumers may be disadvantaged in the type of internet connection they can access as many rural areas do not have broadband connections. To secure broadband access, a minimum of 500 people in an area must make a request for this service. This creates a sub-divide in internet access, as although most people have the potential to access dial-up services, this is not the case for broadband. Part of the *Cymru Ar-Lein* strategy aims to provide broadband facilities throughout Wales by March 2007 (National Assembly for Wales, 2001a). Selwyn *et al.* (2005) describe a vision of internet use based 'e-topia' with universal access to the internet. However, this is unlikely in the near future for many of the reasons outlined above.

2.4.2 Internet access

Data from the Nua Internet Surveys (2002) estimated that over 600 million people use the internet world-wide and that nearly a third of these are from Europe. Use of the internet has rapidly increased with 65% of people in the UK having accessed the internet at some point and 52% with internet access at home (ONS, 2005b). Interestingly, a similar survey conducted some years earlier (ONS, 1998) revealed much lower levels of access at around only 9% of the population (2.2 million households) with home access to the internet. A MORI Survey which aims to track use of technology recently found that 57% of adults (aged 15+) used the internet, compared to about 10% in an earlier survey (MORI, 2005a).[2] In contrast, the Harris Poll suggests that internet use has plateaued with only a 4% increase of internet users from 63% to 67% during the year 2000 to 2002 (Taylor, 2003)[3]. Welsh consumers lag behind the rest of the UK, with a significantly lower number of people connected to the internet. In 2003 half of UK households had access to the internet at home compared to only 37% in Wales (Welsh Consumer Council, 2003). Survey research can provide useful estimates of internet use, however it is acknowledged that market research is commercially driven and so the generalisability of the findings can be limited.

Figure 2.1 shows trends in home access to the internet by household since 1998 and suggests that following an initial surge of new online users in 1999-2000, this has now stabilised. A MORI Survey of internet use in any location demonstrated similar usage to the ONS figures (MORI, 2005b). Despite the deceleration of internet uptake, it is anticipated that those accessing the internet for the first time will continue to increase. A variety of estimates of internet use have been offered, however, these are all likely to be conservative as they do not include those who have indirect access, for example through a friend or relative and so they may mask true numbers of people who have any type of access.

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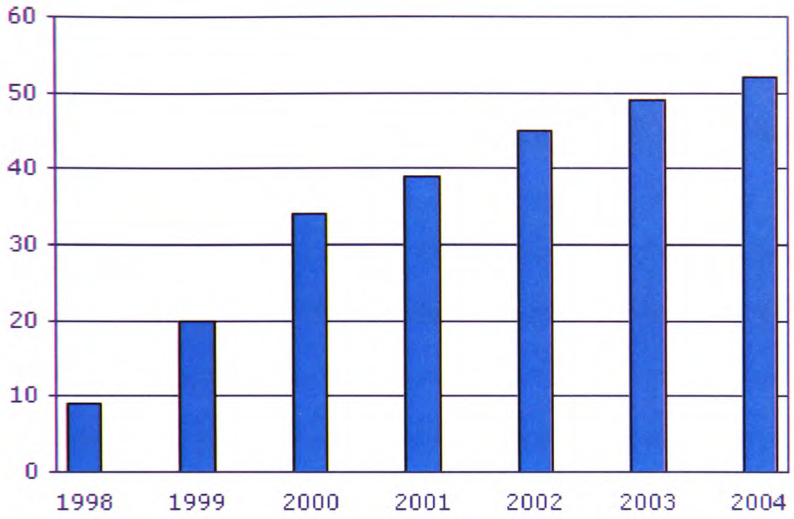
[2] Each monthly report is based on a representative sample of approximately 4,000 adults aged 15+ in the UK

[3] Each Harris Poll is based on approximately 2,000 interviews with adults (aged18+) from the USA

Figure 2.1 Percentage of UK households with home access to the internet; 1998-2004 (October to December)



Source - ONS (2005a)

Table 2.2 provides a comparison of use of the internet by gender and home access in the UK and the United States. Generally, around two thirds of people use the internet, with about half having access at home. With the exception of one study, men use the internet more than women. Gender differences are particularly apparent in the recent ONS studies with a 7% difference between use by men and women.

Table 2.2: Internet use; access and gender *(*Indicates US)*

Study	Internet use (%)	Use by gender (%)		Home access (%)
		Men	Women	
MORI (2005a)	60	52	48	-
ONS (2005b)	59	61	54	52
Harris Interactive (2003)*	67	50	50	57
Fox and Rainie (2002)*	58	60	56	-
ONS (2002a)	57	62	55	45

The internet is becoming increasingly important in health care, both within the health service and for personal use by patients. The second part of this chapter will focus on use of the internet in health care by health professionals and patients.

2.5 Cyber-consumers and health

The internet is a powerful resource which contains extensive information about virtually any topic. When the term *health* was typed into Google, a popular search engine, the results produced 868,000,000 hits (accessed April 2005). This search gives some indication of the expanse of information that is available. Numerous websites focus on health topics from common cancers to rare conditions. There are more than 10,000 health websites, representing over 2% of the websites available (Powell, 2002). One such example is the NHS Direct information web-site, which had 5.2 million hits in December 2000. The internet is distinct from other sources as it has opened up global access to information that has been produced by anyone with the access and skills to develop internet resources. Patients can now access health information about specific illnesses or more general lifestyle issues in the convenience and privacy of their own home.

Health information is currently one of the most popular searches performed online (Fox and Rainie, 2000). Many patients choose to seek health information on the internet in order to improve their health status. Research confirming that the internet is widely used by patients is currently dominated by survey data from the United States (Pennbridge 1999, Fox and Rainie, 2000; Harris Interactive, 2002a). In an audit of one of the highest rated relevant journals, the *Journal of Medical Internet Research*, the researcher found that only 2 (6%) of original papers from 34 published in 2004 were conducted in the UK. Most (59%) originated from the United States which illustrates the dominance of American research in this area.

Recent data reveal that about 75% of users in the US have searched online for health information (Fox, 2005; Harris Interactive, 2005). Surprisingly, these figures represent similar proportions to surveys conducted in 2002, so the trends would suggest that the health internet use has hit a plateau. Reported use in a set period of time reveals much lower usage rates with only 40% (n=1905) of users from the United States accessing the internet for health information during the past calendar year (Baker *et al.*, 2003). By contrast, less is known about consumer use in the UK.

Figures vary from 29% ever accessing health information (Sparado, 2003) to 57% of respondents using the internet for health information during the past year (Datamonitor, 2002).

Differences in defining health internet users can be problematic. For example, some classifications are based on 'ever having used the internet for health', whereas others look at 'use during a set time period'. A person may have access to the internet, but may not actually make use of it. Moreover, a more common trend is using the internet to search for information on behalf of others, for example children, friends or relatives. It is estimated that about half of online searches are carried out for others (Fox and Rainie, 2002). Although accurate figures are not available, and comparisons are difficult, there is little doubt that a significant number of consumers who have access to the internet use it for health information. There is new evidence to suggest that those with broadband are more likely to access health information than those with dial-up access. The new breed of 'power users' (those with six or more years of internet experience) may use the internet increasingly for everyday concerns, rather than specific conditions (Fox, 2005). This type of use reinforces the social inequalities in accessing different levels of technology and the importance of universal access to information about health care (Eng, 1998). There are also indications to suggest that internet users are healthier than non-users (Cotton and Gupta, 2004; Dutta-Bergman, 2004). Possible explanations include, health benefits resulting from accessing information, and more frequent use of the internet by younger age groups. Internet users are also likely to have a higher socioeconomic status. One objective of this project aims to examine in more detail how patients actually use the internet and their perceptions about making the most effective use of the internet for health improvement.

2.5.1 What type of consumers search for health information online?

Goldsmith (2000) claims that with the exception of e-mail, health information is the main reason why women use the internet. One possible explanation for this is that women usually assume responsibility for the health and well-being of their families

and so are more likely than men to actively seek health information in general (Graham, 1984). Most surveys of health internet consumers highlight that the majority are middle aged and tend not to be the significantly older or very young patients. Use declines as age increases (Fox and Rainie, 2001; Health on the Net Foundation, 2001); however, even in older groups there is a notable increase in use (Age Concern, 2001). There is evidence that younger populations also use the internet for health information (Borzekowski & Rickert 2000). It would appear that the majority of internet users tend to be from younger, well educated groups. However the profile of internet users is changing with a marked increase in the number of older internet users and those from lower socioeconomic groups. Jones *et al.* (2001a) consider the use of Touch-screen kiosks as having a greater potential with older populations than the internet. They found that over a third (n=23) of patients aged 50+ would use Touch-screen kiosks in the future (on site) compared to only 7% (n=4) predicting their future internet access at home.

Many people choose to use the internet as a source of information. When the motivations behind such use are considered, a common assumption is that people use the internet because it is a readily available source for those who have access. The internet is often viewed as an alternative medium to other sources. Although accessibility is an important consideration, the internet enables people to cross geographical and cultural boundaries. The internet promotes new forms of communication; in some situations patients may favour the anonymity this resource can provide, as they can share intimate feelings without risk (Joinson, 2003). Anonymity can be adopted in a functionalist way by using this form of communication to preserve self-presentation (Goffman, 1959: 107). The internet can be viewed positively as promoting increased dialogue between patients, however there is also a risk of social isolation as a person may seek others with similar interests and only communicate with these groups.

2.5.2 What do patients do online?

Patients may benefit from using the internet in a variety of ways. For example, the internet offers patients the potential to access a range of health information far in excess of more traditional approaches, including world-wide sources. Cline and Hayes (2001) describe tailoring of information in their review of health information seeking as a key benefit of the internet. They refer to the potential for patients to select information according to education, language and format. However, this contention assumes that patients may have the capacity to make these types of selections.

Users may merely browse websites that focus on fairly general health information, or may make more extensive use of the information by self-diagnosing a health problem (Raupauch and Hillier 2002; Williams *et al.*, 2003). Parents frequently seek information online to diagnose or treat child illnesses or to seek advice about parenting (Berhardt and Felter, 2004). Health care professionals are also now likely to encounter many patients who bring in printouts from the internet (Patrick, 1999). However, the limited evidence to support such use is derived from small samples and clearly indicates a need for further research in this area.

Patients may access websites that are designed to answer questions, or provide material that is intended for discussion in consultations. For example, My Expert Doctor https://www.myexpertdoctor.com/Home.asp offers a personalised approach to health information in which patients provide details about their medical history and receive a list of questions to ask their doctor. This interactive tool may be welcomed by the patient, but may offer an even greater challenge to the doctor as the patient may already be receiving specialist advice. Some patients may look for information about service providers. They may check performance indictors such as hospital league tables or the number/type of treatments carried out, for example the number of Caesarean sections. This information may then be used to decide (when feasible) the most appropriate place to receive treatment. Although such usage is more prevalent in countries with privatised health care, it is likely that this practice

will increase in the UK, especially in the light of the poor publicity that some NHS trusts have received in recent years and the government's intention to publish league tables.

Over three quarters (77%, n=1116) of patients in the Health on the Net Foundation survey (Health on the Net Foundation, 2001) sought information from medical websites, and the most frequent use (86%, n=1302) was for patients seeking information about drugs. This research supports the assertion made by Meredith (1995) that patients need to be suitably informed about the drugs they take. Patients are more likely to use the internet to seek details about specific conditions than for general health information such as lifestyles. The Pew American Life Project found that nearly all health seekers (91%, n=3209) searched for information about physical illness in comparison to only 13% (n=459) searching for information about fitness and nutrition (Fox and Rainie 2000). In a small cross-sectional survey of primary care patients, Sciamanna *et al.* (2002) found that just under half of internet users (n=92) went online to find questions that they should ask their doctor. Patients searching for information about an illness are more likely to encounter complex information, which may be intended for health care professionals. Assimilation of this information may need to be facilitated by health professionals. For example, patients intending to purchase medication, or access complementary therapies may wish to discuss this with a health professional. Woloshin *et al.* (2003) describe the use of web-based risk calculators which can put the patient's health risk into the context of their own potential risk. They refer to three important principles: clarity about risk, context, and acknowledging uncertainty, which much be used as the basis of providing patient information. Woloshin *et al.* (2003) claim that no matter how advanced the data are, they have to be meaningful to the patient. The internet can provide patients with sophisticated tools to interpret health information. However, there is no guarantee that the information is relevant to the individual needs of the patient.

Patients may use the internet to communicate with health care professionals about a particular condition. For example, Eysenbach and Diepgen (1999) investigated 209 unsolicited e-mails sent to physicians about dermatological conditions. The greatest

motivation for sending the e-mail (81%) was from patients with a chronic illness/condition who were seeking a second opinion. This form of self-referral reveals how resourceful some patients can be if they want information about a particular condition. The Health on The Net Foundation (HON) survey described earlier also provided evidence of patients using the internet for a second opinion (Health on the Net Foundation, 2001). Just under half (43%) sought a second opinion and only 14% used e-mail to contact their own health care professionals. This may be because an increasing number of patients are not satisfied with the care they receive. On the whole, patients may appear to be satisfied, but it is important to consider the many limitations of the internet, for example concerns about the quality of information on the internet.

Sciamanna *et al.* (2002) found that the most common request of patients from the United States for potential internet use was to find out whether they were having the tests and treatments that were needed. Using the internet in this way may have bigger implications for the US system where patients are more likely to be concerned about value for money. Despite the extensive ways that patients currently use the internet, there may be a deficit between what patients are actually doing in comparison to what they would like to do.

2.5.3 Consumer groups

The increase in consumer activity in relation to health care has led to a rise in user groups. A number of these are well established and have been in existence for some time. In the past, many of these groups were influenced by health professionals, however more recently they have been set up due to disillusionment with the health service and a desire by patients to have greater involvement in managing their own health. Online support groups have gained increasing popularity. E-mail is the most basic and widely used form of teleconverse, but electronic communication has now progressed into the development of online discussion groups, self-help mail-lists and chat rooms in which experiences are shared and discussed in the form of a support network. It is estimated that one in four internet users joins an online

support group (Cyberdialogue, 1998). These exchanges may provide an alternative form of support or may complement more traditional care received by health professionals. Accessibility is an obvious advantage of support groups which are not governed by the constraints of time. In a qualitative study of two online health communities, Macintyre (2003) found that one advantage of chat rooms is that they offer participants the opportunity to talk simultaneously in a live format rather than communicate in a static form through e-mail. There are numerous examples of online support groups which are developed and maintained by patients, such as the Multiple Sclerosis Discussion Forum (MSDF, http://www.mssociety.org.uk). There is, however, the potential for participants to abuse such systems by posting inappropriate messages. Although discussion fora can be managed, for example, by a relevant stakeholder or governing body, there are currently few regulations about the use or potential abuse of discussion chat-rooms. This is an important concern as patients' use of online support groups is likely to increase as consumers gain more confidence and skills in their use of the internet.

2.6 Quality of health information

There are many advantages to using the internet, such as convenient access and the potential to obtain a wide variety of information. However, there is increasing evidence that questions the quality of health information on the internet (Kunst *et al.*, 2002)[4]. Primarily, it is currently an unregulated source through which anyone can provide or access information. The internet has not only increased the possibility of patients accessing information intended for health care professionals but may also put patients in a vulnerable position as they may encounter information which is unreliable, of poor quality, difficult to understand, or may not even apply to their health care needs and that they use such information erroneously.

Although there are widespread concerns about the quality of information, this is not a concern for all patients. Diaz *et al.* (2002) surveyed patients about their use of the

[4] In 2002 the BMJ published a theme issue about the quality of health information on the internet (324; March 2002).

internet and found that 62% (n= 168) rated internet information as 'excellent' or 'very good' with no respondents rating it as 'poor'. Those with lower education levels were likely to give higher quality ratings. A Harris Poll in the same year found that nearly all respondents from France and US (93%, n=636) considered online information to be trustworthy (Harris Interactive, 2002b). However, more recent research suggests that consumers do question the information they access. In a study investigating trust of information on the internet, about half (48%, n=635) expressed that they could only believe some of the information they accessed (Huntington *et al.*, 2004). About half of the consumers checked the source of the information. These findings could be an overestimation as some consumers did not wish to admit to a lack of vigilance when seeking health information. This study was based on a sample obtained with assistance from The Independent newspaper and so is likely to be less representative of the wider population due to the readership bias.

One concern about patients' use of the internet is that they may encounter biased information that lacks credibility, authority and trustworthiness (Eysenbach, 2000b). A number of initiatives have been developed to provide a form of quality control on the internet. A review of instruments to rate quality of health information on the internet identified 98 instruments, yet many of these were incompletely developed (Gagliardi and Jadad, 2002). The National Electronic Library for Health (NeLH) has set up public access to evidence based sources of information. These tools assist patients who choose to use this resource, but also help health professionals to guide patients in their use of the internet (www.nehl.nhs.uk). The HON Foundation has probably the best established code of conduct based on eight standards for internet information and is used by thousands of websites (Wilson and Risk, 2002). These quality assessment tools and kitemarks are recognised by some health professionals and web developers, yet it is likely that many patients are unaware of their use or meaning and so may not use these tools to evaluate the information accessed. This situation is somewhat ironic given that patients are in the greatest need of quality indicators.

2.6.1 Internet searching strategies

The patients' ability to use information technology was briefly explored earlier in this chapter. Although there are training courses available that aim to develop internet searching skills, most users are likely to be self-taught. Peterson *et al.* (2003) investigated the searching techniques that patients use to find information about medicines. This qualitative study presented an in-depth exploration of the searching behaviour of patients and found that the majority use simple search engines which ranged from basic key word searches to more advanced techniques. Although this was a small scale study, it provides a useful insight into what patients do. It also raises the importance of educating patients to provide them with searching skills. Bernhardt and Felter (2004) found that most patients used search engines but also used named websites identified through advertisements and word of mouth. It is evident that the internet proficiency of health professionals can have a significant impact on whether they themselves find the internet useful. Overall proficiency at using computer systems, for example paperless practices and the use of e-mail is strongly associated with the perceived usefulness of the internet (Pemberton *et al.*, 2003). Further attention should be given to exploring and understanding the strategies patients use to search for health information in order to maximise the potential value of the internet.

2.6.2 Personalised information

One of the greatest problems with the internet is that the information is not personalised to the individual patient. Despite the increased drive towards tailoring information, generic sources on the internet rarely account for personal demographics such as age, gender and health risks. Tailoring information that is unique to the patient is much more meaningful for the patient (Coulter, 2005). Currently, health professionals have a central role in assisting patients to apply information to their specific needs. The reluctance of some doctors to embrace internet informed patients may result in patients experiencing difficulties in achieving patient-tailored information (Jones, 2003). A lack of continuity of care

may also have implications for managing information as patients may be less able to discuss information with a GP that they do not know. A significant development for patients is the electronic health record (EHR). Electronic records have the potential to provide patients with information that is relevant to their personal health and greater control over their personal health information (Welsh Assembly Government, 2002a). Electronic access to an individualised record has provided patients with the opportunity to affect their care management in a more influential way, perhaps, by presenting preferences for treatments, or using information to seek alternative medicine for unresolved health problems. The importance of personalised information is a growing concern for patients and health professionals. An extensive UK survey of 110,000 people comprising members of the public, NHS staff, voluntary organisations and professional groups found that having the right health information suited to personal needs was important. Nearly all respondents stated that they needed more information to make decisions about health care (Department of Health, 2003). Pagliari, *et al.* (2004) support the introduction of computerised patient records (CPRs) and conclude in a review of research that:

> 'Studies of patient-accessible medical records suggest modest improvements in doctor-patient communication, adherence, patient empowerment and patient education' (p114).

They acknowledge that current evidence is based on small-scale research and warrants further investigation.

Personal electronic health records have the potential to empower patients by providing increased communication with health professionals and enabling them to annotate their health record. However, much of the current use has only been implemented to assist the exchange of information between health professionals. Recent service statistics for *Connecting for Health*[5] reveal that 64, 846 primary care prescriptions have been transferred electronically to the pharmacy using the Electronic Transmission of Prescriptions and 17, 849 appointments have been made

[5] Connecting for Health is an agency of the DoH responsible for delivering the National Programme for IT.

using the Choose and Book system (Department of Health, 2005a). The Choose and Book system is available for health professionals and patients in England to arrange secondary care appointments online or by phone at a time that is convenient for the patient. Although this offers greater flexibility for patients, these figures do not indicate the extent to which patients have access to this system in comparison to primary care professionals. It is likely however that EPRs have potential for offering a more personalised approach to patient information. However, for many patients, the internet still remains a generic source of information which is only tailored to their needs if they discuss the information with their health professional.

2.7 Health and the internet; the doctor-computer-patient interface

Medical training of doctors has always put an emphasis on memory and the ability to store knowledge. Expectations of primary care professionals to recall diverse information and to perform in many fields are exceptionally high; doctors are often open to criticism if they reveal a tendency to look things up. In reality, it is impractical to expect a person to have a perfect ability to store and retrieve an abundance of information (Slack, 2001). With this in mind, in the early 1960s, the use of computers in medicine was explored as an aid for doctors and patients. This interest stemmed from two main reasons, firstly, the potential that computers could have in clinical diagnosis and secondly, 'patient power' (Slack, 1972). The computer therefore seemed an ideal medium through which both doctors and patients could enhance treatment and care.

During the past few decades, health services globally have undergone extensive technological developments, transforming many medical practices. Use of the internet as a means of communication has been a central part of ICT policy (Department of Health, 2002a). Patients with chronic conditions, such as asthma and diabetes, could soon be receiving text messages with advice about healthy lifestyles making self-care a real choice (Department of Health, 2005b). The National IT programme (Department of Health, 2002a) aims to develop a basic electronic health record for all patients which would provide instant access to patient records

through a secure server. A feasibility study of the use of EPRs in three general practices has shown that patients supported this development and did not wish to limit access to their records (Adams *et al.*, 2004). Concerns about confidentiality and consent have been described as the greatest barriers to the EPR; however these issues did not impede their use.

Use of the internet by health professionals has dramatically increased in recent years (Howcroft and Mitev, 2000). Although clinicians continue to rely primarily on paper based information, it is likely that online resources will become a more important resource for clinicians. Using e-mail as a form of communication internally and externally is now a common feature of many health care settings. Online discussions between patients and doctors have gained popularity, more recently as a form of problem-based learning (Wass *et al.,* 2003). Nearly all general practices in the UK (96%) have a clinical computer system with half of these having access to the internet (Pemberton *et al.*, 2003) These figures demonstrate that computerised systems are now commonplace in primary care. However, despite this widespread access, many systems are underused in general practice (Gillies, 1998).

A common assumption is that resistance to using computers by health professionals is due to computer phobias or poor computer literacy. Although in some situations such claims could be supported, computers are accessed by a wide range of users and so it is unlikely that poor literacy is the greatest barrier to using technology. Early work into the use of computers in primary care indicated that their use could adversely affect communication between the doctor and patient (Greatbach *et al.*, 1995). Although it was possible for doctors to engage in simultaneous use of the computer and discussions about unrelated topics, greater flexibility of the system design was needed to further facilitate this process. Slack (2001) suggests that limited use of computerised systems are far more likely to be as a result of bureaucracy than the actual technology. In the past, computers have been portrayed as time consuming and costly which had significant consequences on their application in health care. Often, the reason for non-use of systems can also be attributed to poor design. For example, computerised decision aids are often developed with little or no regard for the patient or clinician. It is necessary to

consider the needs of the users from the outset to avoid such problems. McAlearney (2004) demonstrates that given the right application, use of technology such as handheld devices can be a positive experience. There is also a strong drive in the NHS to ensure that health professionals have adequate ICT skills by offering schemes such the European Computer Driving Licence (ECDL)[6].

The internet can be used as a means of bridging the link between health professionals and patients, for example through e-mail or patient focussed websites. An innovative example is demonstrated by the James Wigg Practice in North London which has received NHS Beacon status[7] for ICT. Patients have the ability to use e-mail, access patient records and results, and book appointments online. These developments illustrate the future potential for the transfer of some care, repositioning the management of health and illness to the patient in their home setting. Teleconverse may soon be commonplace in the management of health care through electronic contact between patients and physicians. These initiatives place a greater responsibility on patients, which could ultimately lead to an increase in preventative medicine.

Consumer health information systems such as CHESS (Comprehensive Health Enhancement Support System) have been designed to offer information, communication and web-pages aimed at facilitating behaviour change (Gustafson, 2002). The internet has also reached new levels of sophistication by offering innovations such as online consultations. Computers clearly have the potential to enhance treatment and care. The technological developments in medicine are widespread; however there is still resistance to using computers in the doctor-patient dialogue. The increasing use of technology has the potential to transform the health service; however, there have also been significant changes in approaches to medical practice.

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[6] Further details about the ECDL can be obtained from the British Computer Society (http://www.bcs.org/server.php?show=nav.5829).

[7] NHS Beacon sites are awarded to practices that have excelled in particular areas. This status is awarded so that these sites can help other parts of the NHS learn from best practice.

2.8 Contemporary health care - a time of transition

In recent years, medicine has experienced some notable changes with a slow departure from the widely established medical model. Traditionally, medicine has been dominated by the biomedical model, based on the assumptions that illness manifests itself in a physical way (Salmon and Hall, 2003). A clear distinction is made between the mind and body, often defined as 'mind-body dualism'. Yet this style of medicine has been highly criticised as it advocates a reductionist approach that ignores holistic perspectives. In the latter half of this century, medical professionals have gradually acknowledged the multifaceted nature of health and illness by adopting more social models of disease (Turner, 1995: 9). This change stemmed partly from an awareness that diseases such as Tuberculosis declined before immunisations were available and coincided with improvements in social health (McKeown, 1979). Lifestyle factors were also recognised as having an influence on susceptibility to disease, for example, nutritional status. This in turn prompted a focus on more chronic conditions, such as asthma, and healthy lifestyles in general, rather than infectious diseases.

The early work of Parsons (1951: 440) examined the social role of illness using a functionalist approach to medicine. Parsons introduced the concept of the 'sick role' in which illness was perceived as a form of deviance and so the sick have an obligation to get better as soon as possible. However, in this scenario, the patient is dependent on their doctor who acts as the gatekeeper of the sick role. Although this concept attempts to focus on social processes, it reinforces the power of the medical profession based on the biomedical model.

Emphasis has been placed on social constructionism, in which theorists have further examined the social issues of the biomedical model. The inherent belief is that explanations of disease are not fixed, but are reconstructed over time and the social aspects of health and illness make a valuable contribution to the medical discourse. However, there is an ongoing debate about the limitations of constructionist

analyses. Lupton (1994) presents one of the common criticisms targeted at this approach:

> 'Constructivist analyses have been criticized for concentrating upon medical discourse at the macro-level, for making broad generalisations and avoiding a detailed examination of the micro-context in which the discursive processes take place, such as everyday experiences of people....' (p 12).

It should, however, be acknowledged that it is often these very issues that are investigated through a social constructionist perspective. Broader perspectives of health care have slowly promoted a more individualised approach to care. Exchanges in the clinical area such as 'the bronchitis in bed 4' are now less commonplace. They have been replaced with an approach which considers the patient first rather then their disease. Engel (1977) famously introduced the biopsychosocial model resulting from his beliefs that medicine was in crisis due its reliance on models of disease. The model comprises biological (genetic, brain and chemistry), psychological (person's beliefs or behaviour) and social (status in the community, or relationships) components and attempts to understand patient illnesses in that context, resulting in a radical shift from traditional medicine.

The move towards more holistic approaches to care is supported by health professionals. However, strong drivers for this change also come from patients calling for an end to medical dominance that has been reinforced by the fallacies of modern medicine (Allsop *et al.*, 2004). There is also a realisation that the patient can have a greater input into their health in a way that goes beyond mere medical concerns. Health is no longer governed exclusively by biological determinants. Focusing on psycho-social features and patient outcomes presents new challenges to doctors as they must encounter and deal with patient perceptions of ill health as well as physiological causes. Medicine has experienced an ideological shift, with the consultation moving towards one of negotiation between professional knowledge and lay beliefs. The doctor-centred model of clinical encounters has, therefore, been challenged by both patients and from within the medical profession, resulting in an increasing focus on patient-centeredness (May *et al.*, 2004).

Evaluations of medical effectiveness must be placed within the context of patients' lives rather than within doctors' hospitals (Sullivan, 2003). Primary care is a key setting for this approach as the patient should be cared for first and the disease second. However, although medical curricula include Engel's biopsychosocial model, this philosophy of care is not necessarily embodied in practice. Irvine (2004) suggests that medicine has developed as a profession, but this progression is not consistent with patient needs:

> 'In the 20th century, the professional was vigorously progressive in developing medical science and technology, while remaining deeply conservative on matters of attitude and human relationships about which patients care greatly. Attitudes to paternalism, communication and patient consent exemplified this' (p 272).

Medical practice has experienced many changes; however, despite attempts to adapt to rapid developments in the structure and provision of health care, many health professionals continue to rely on traditional approaches to care.

2.8.1. Doctor-patient relationship – care and conflict

So far, this chapter has illustrated the role of the patient within a changing health care environment. The doctor-patient relationship has been one of the most significant areas of change, particularly in terms of how patients perceive the medical profession. Lupton (1997) conducted research into lay people's views about medical practitioners, which produced a balance of supportive comments and criticism. Many participants hailed back to their childhood and described experiences of when the doctor had come out to see them at their house. This view of the social authority of the doctor remained unchanged for some respondents who felt that patients should not challenge the doctor. Some described the need to have a close relationship with their doctor, whereas others preferred a 'professional distance'. Many patients endeavour to take more of an active role in consultations

yet others prefer to act more passively. Some of these differences can be attributed to the characteristics of the patient, such as age, gender or their beliefs and ideals about health, which affects the way they approach the consultation. Donaldson *et al.* (1991) found differences in perceptions of the doctor according to age and social class. University educated patients and elderly people have a more positive attitude about increased patient involvement in consultations. Those in professional education were happier to challenge the authority of the doctor.

For decades the primary care consultation has been under close scrutiny, offering a plethora of consultation models (Neighbour, 1987; Cohen-Cole, 1991; Mead and Bower, 2000). Roter *et al.* (1997: 350) offer four different approaches to consultation style:

1) Paternalism – doctor-centred style
2) Consumerism – patient in control
3) Default setting – neither party takes responsibility
4) Mutuality – both doctor and patient are involved in a process of negotiation

In reality, it is likely that consultations consist of a blend of these practising styles. Pendleton *et al.* (2003: 7) refer to a cycle of care in relation to the consultation process. This cycle involves immediate and long-term outcomes for the patient, but has been criticised for the absence of process issues in relation to communication issues during the consultation (Beckman *et al.*, 1989).

The information explosion on the internet further challenges the dynamics of the doctor-patient relationship. Central to the doctor-patient relationship is the understanding that each person brings different experiences, expertise and expectations to the interaction. Patients may not act in a rational way. For example, the fact that they are receivers of information does not mean that they will use this information to make changes to their behaviour. Due to the ever increasing demand on the health service, alternative forms of services have been provided such as NHS Direct, which may even replace the need to visit the doctor. High-tech information

has the capacity to act as a replacement for the oral communication from health care professionals, or as a substitution to shield doctors from their patients.

Health professionals approach the primary care consultation with pre-determined beliefs, many of which have been internalised over time as a result of experience and education. In addition, there are more localised concerns, such as the mood of the practitioner on the day, appointments schedule, and the patient with whom they are dealing. Pendleton *et al.* (2003) outline these factors in the cycle of care, which determines the success of the consultation. One GP may approach a patient very differently to another. Extensive research has been conducted on how doctor-patient communication can affect the consultation (Ong *et al.,* 1995). Some patients may prefer to consult with a particular doctor when accessing primary care as they already have an established relationship. Due to the increasing pressures on primary care resources, these needs can not always be accommodated. The doctor-patient relationship is also exacerbated by the new GP contract (BMA, 2003) as patients will no longer have a named doctor allocated to them, but will consult with whatever doctor is available. Doctors may also hold beliefs about patients based on negative stereotypes such as hypochondriacs or heartsink patients (O'Dowd, 1988). Heartsink patients have been described as those who often have unresolved health concerns that can not be addressed through medical means, causing the GP to feel helpless during consultations (Pendleton *et al,* 2003). This classification is bound by subjectivity as GPs who describe fewer heartsink patients may be more tolerant, or conversely those with higher rates may be less tolerant by categorising a greater proportion of patients in this role (Mathers, 1995).

Increased regulation and the rise in more informed patients have all impacted on medical dominance and may at least in part have contributed to some deprofessionalisation. It is argued that further work is needed to establish whether the more informed patient does indeed challenge the medical profession or whether this type of patient promotes health care partnerships (Hardey, 1999).

2.9 The internet and primary care consultations

It was well into the 20th century before medical information was available to the masses. Prior to this, attempts were made to withhold information from patients. For example, prescriptions were written in Latin so that patients could not understand them (Slack, 2001). Patients no longer have to rely on the medical profession for information, but can interact with electronic information via the internet. An important consideration is that, in the majority of cases, face-to-face contact is necessary to determine the most suitable health care. In a survey of primary care patients from the US, Diaz *et al.* (2002) found that 11% (29 of 266) had used the internet as a replacement to visiting the doctor. It should be noted that this postal survey identified significantly more internet users with a college education and high earnings which could explain some of the reasons for use and non-use. Despite the small proportion indicated by Diaz *et al.,* it is a sign that patients are not afraid to take on such a responsibility. Ferguson (2002) estimated that a patient would only have to search online for an hour to gain the same amount of knowledge about their condition with which their doctor was not familiar. Jadad (1999) predicted that the internet would have a profound effect on the doctor-patient relationship. At this time there was little evidence about partnerships between patients and doctors using the internet. Much of the research on use of the internet in consultations has since been conducted on behalf of patients, rather than gaining their viewpoint.

Use of the internet in consultations can take one of three forms. Firstly, the internet can be used to have a virtual consultation online; secondly it may comprise searching for information online during face-to-face consultations and lastly it can be used by referring to internet information that was accessed prior to the consultation. An increasing number of patients bring in information that they have accessed from the internet for discussion in primary care consultations (Murray *et al.*, 2003). Such claims are primarily reported from GPs' experiences in consultations, rather then directly from patients. For example, a poll by the BMJ, found that 88% of GPs had consultations with patients who had brought information from the internet (Ferriman, 2002). Although the methodological rigour

of this opinion poll is questionable, GPs voiced their support for the move towards patients taking on a more active role in consultations. However, health care professionals may not encourage internet informed patients who may be perceived as a challenge to the traditional role of the GP (Wilson, 1999).

The limited research available that explores patients' use of the internet in primary care suggests that about half of internet users discuss internet information in consultations. Diaz *et al.* (2002) found that 41% (n=110) of internet users discussed information accessed online in subsequent consultations with their doctor. Houston (2002) revealed in a telephone survey of health internet users that over half of those with poor health status discussed internet information with health professionals compared to less than a third of those with higher health status. Clearly, many patients are willing to discuss internet information during consultations. It is therefore important that primary care staff are aware of such requests and are equipped to facilitate patients in using internet information.

Although patients may seek further advice from health care professionals about information they have obtained from the internet; in practice this may not always be welcomed. Opinions about whether the internet is a useful source of information for primary care staff during patient consultations seem to vary. The results of a survey (n=160) which examined the impact of the internet on primary care staff in Glasgow (Wilson, 1999) indicated that 58% of doctors and 34% of nurses had encountered patients who had produced internet information during a consultation. These patients had much higher expectations than average. Significantly more practice nurses than GPs felt that they could use the consultation time more effectively with internet informed patients. Eberhart-Phillips *et al.* (2000) surveyed GPs (n= 168) in New Zealand about their use of the internet. Seventy-one percent of GPs had patients who had accessed it for health information. In addition, almost half of these GPs felt that patients' use of the internet would be a potential source of conflict between the doctor and patients and only 15% felt that it would improve the doctor-patient relationship. Diaz *et al.* (2002) suggest that doctors' reluctance to ask patients about internet information could account for non-use of this information during consultations. A recent UK survey (n=181) by Malone *et al.*

(2004) found 74% of primary care professionals had been presented with internet information from patients; most of this occurred once a month or less. Follow up interviews with a small sample (n = 8) revealed that presenting internet information post-diagnosis was more accepted than pre-diagnosis. These studies indicate that some primary care practices may not be sufficiently prepared to deal with internet informed patients.

Hardey (1999) suggests that the internet challenges the biomedical model of information giving, which is central to the move towards deprofessionalisation. He contends:

> 'The basic design of the internet therefore represents a challenge to previously hierarchical models of information giving. This shift in control is central to the deprofessionalisation thesis and may be seen as contributing to the decline in awe and trust in doctors' (p 832).

Hardey (1999) proposes a pluralist approach to health care based on the use of existing sources and new sources. On one hand, the information crosses professional boundaries, but on the other, interactive resources may encourage new and more diverse interactions between patients and health professionals. It has been suggested that health professionals feel challenged by the internet, yet there is less of a focus on patient experiences of using the internet in primary care. A key aim of this thesis is to explore patients' experiences of using the internet during primary care consultations and consider how doctor-patient relationships are being influenced.

2.10 Operationalising patient-centred care in the information age

This chapter has highlighted the potential use of the internet for patients in the context of contemporary health care. The internet has been described as having made a significant contribution to informing patients and providing new applications in the delivery of health care. The following section considers these issues in the context of patient-centred care, a concept which is used to underpin this thesis. Particular consideration is given to how the internet may impact on patient-centredness in primary care.

Patient-centred medicine was first introduced in the 1950s with attempts to move away from models of illness and to acknowledge biopsychosocial perspectives (Balint, 1957). This term is now widely adopted, often without truly considering what is meant by patient-centred care. In this thesis, patient-centred care focuses on the informed patient in primary care. A review of recent literature on patient-centred care revealed an extensive range of definitions which supports the complexity of this concept. Table 2.3 provides a comprehensive list of the most common dimensions of patient-centred care based on empirical evidence from the literature.

Table 2.3: Definitions of patient-centred care

Dimensions	Study
Shared power and responsibility (partnership)	Kinnersley *et al.* (1999) Stewart *et al.* (2000) Mead and Bower (2002a)
Holistic approach (patient as person)	Stewart *et al.* (2000) Little *et al.* (2001) Mead and Bower (2002a)
Enhancing the doctor-patient relationship	Stewart *et al.* (2000) Little *et al.* (2001)
Access to information	Kinmonth (1998) Kinnersley *et al.* (1999) Mead and Bower (2000) Stewart *et al.* (2000)
Communication	Kinmonth (1998) Little *et al.* (2001) Mead and Bower (2002a) Stewart *et al.* (2000) Tarrant *et al.* (2003)
Individualised treatment	Balint (1969) Tarrant *et al.* (2003)

Stewart *et al.* (2001) have worked extensively in this area, most notably introducing the patient-centred clinical method. They offer an international definition of patient-centred care:

> *Patients want patient-centred care which (a) explores the patients' main reasons for the visit, concerns, and need for information; (b) seeks an integrated understanding of the patients' world – that is, their whole person, emotional needs, and life issues; (c) finds common ground on what the problem is and mutually agrees on management; (d) enhances prevention and health promotion; and (e) enhances the continuing relationship between the patient and the doctor.*
>
> (Stewart et al., 2001: 445).

Stewart *et al.* (2003) describe a 'growing consensus' on the use of this international definition. This may be evident in academic arenas, yet patient-centeredness can be open to interpretation, depending on the motivations of the stakeholders involved. In a recent qualitative study Gillespie *et al.* (2004) investigated clinicians, managers and lay stakeholders views about patient-centred care. A variety of definitions were offered, with health professionals describing a biomedical model *'with professional priorities determining patients' needs* (p 45). In contrast, user groups described a more social or holistic approach to care. Although this study aimed to investigate patient-centred care on an individual level, many referred to patient care on a wider scale, which could be more aptly described as patient and public involvement. Gillespie *et al.* (2004) appropriately pointed out that it may mean different things on an individual level; however, there was a need for a working definition to *'encompass the full range of activities'* of patient-centred care.

Mead and Bower (2000) offer a comprehensive appraisal of patient-centred consultations in primary care in a framework of five distinct dimensions:

1. The biopsychosocial perspective
2. The 'patient as person' – understanding the personal meaning of illness for each individual patient.
3. Sharing power and responsibility – sensitivity to patients' preferences for information and shared decision making.
4. The therapeutic alliance – developing common therapeutic goals and enhancing the personal bond between doctor and patient.
5. The 'doctor as person' – awareness of the influence of the personal qualities and subjectivity of the doctor on the practice of medicine.

The third dimension focuses on the importance of shared power and patient preferences for information. The remaining dimensions also have implications for patients who may wish to refer to internet information in a primary care context. The elements offered by Mead and Bower (2000) will be broadly integrated into this thesis to examine patient-centredness in primary care.

A strength of patient-centred care is that, in principle, the patient should be able to adopt a position that they are comfortable with in relation to their health. Measures to develop a more equal partnership between professionals and patients include the training of professionals in special skills to ensure a shared decision-making approach (Elwyn *et al.*, 1999). However, a criticism of patient-centred care is that patients may not actually desire to be the central player in managing their health care. There is a belief that a transformation of the health care systems and attitudes are necessary in order to provide care that is patient-centred (Kizer, 2002). If effective, this should promote an increased quality and continuity of care and reduction in costs. The importance of patient-centred care in relation to health information is that the patient has the opportunity to request information and to discuss the implications in the context of their individual care.

There is a wealth of evidence to suggest that patients manage their health effectively when they are more involved (Gibson *et al.*, 2002). Yet, the paternalistic approach in the NHS prevails over many interactions leaving the patients despondent or

frustrated. Some patients may wish to take more of an active role in their health by accessing information, yet if these efforts are rebuffed by health professionals, then the potential value of patient-centred care may be lost. It is clear that some doctors find it difficult to acknowledge patient-centred care and consider their current practice to be effective. Jones *et al.* (2001b) recognise the difficulties that health professionals have in meeting the health information needs of patients. In a four-stage multicentre multidisciplinary study, Jones *et al.* (2001b) produced 46 learning outcomes to assist clinicians in meeting the health information needs of patients. The learning outcomes were mainly patient-centred, highlighting the need to place a higher priority on patient information, with a broad aim of facilitating patients' understanding of health information. Organisational changes were also discussed in relation to strategy, research and development, and education. These learning outcomes offer educationalists a focus for the development of future curricula, yet the difficulties of achieving patient-centredness are widely acknowledged (Stewart *et al.*, 2003). Campion *et al.* (2002) concluded in a study on the emphasis of patient-centredness in the Membership of the Royal College of General Practitioners (MRCGP) examination that doctors find it difficult to achieve patient-centred outcomes. Evidently, the constraints and pressures of primary care practice can make it problematic for health professionals to facilitate patient-centredness.

To date, the link between patient-centred care and better patient health outcomes is inconclusive. Research focuses on measures of patient satisfaction, a method notoriously fraught with difficulties. Some of the issues have arisen partly from methodological concerns as researchers have used mainly observational rather than experimental designs. In addition, the multi-dimensional nature of patient-centred care causes difficulties when comparing research that is built on an assortment of frameworks. In the current climate of evidence based medicine, it may be difficult to enhance patient-centred care. Evidence based medicine does not address the individual experience of the patient and reinforces the biomedical model of care, whereas patient-centred care is based on the biopsychosocial perspective which is not sufficiently addressed by the evidence base (Bensing, 2000). Dieppe *et al.* (2002) describe a contradiction between patient-centred care and evidence-based medicine which has the potential to disempower professionals as they may not be able to

provide care that is patient-centred. One way to resolve this is to ensure that the evidence base is more patient-centred and that there is a greater evidence base to support patient-centred medicine. This thesis endeavours to contribute to this evidence base by focusing on the importance of patient-centred care in relation to use of the internet in primary care.

2.11 Conclusion

This chapter presents the modern patient as an active and informed consumer of health. Current use of health information from the internet was explored with a particular focus on using information in primary care. These issues are presented in the context of patient-centred policy and changes in the organization and delivery of health care. The increasing availability of health information and focus on patient-centredness have contributed to a shift in approaches to patient care. It is evident from the literature that use of the internet for health information is widespread. Much of the existing research on internet use is based on descriptive survey data which does not sufficiently explore the potential implications of using this resource. The internet is reported as having a negative impact on the doctor-patient relationship, yet there is limited research to support this claim. This study therefore aims to address the dearth of literature by exploring patients' use of the internet in primary care. The following chapter discusses the methodology needed to achieve this aim.

CHAPTER THREE

RESEARCH METHODS

3.1 Introduction

This chapter presents an overview of the research design of this study. The methodological considerations that underpin the design are examined. An overview is then presented which outlines the three phases of the study. In Phase 1 patients were surveyed about their use of health information sources. Phase 2 comprised a series of interviews with patients and staff to explore patient and professional perspectives about using internet information in primary care consultations. In the final phase an online discussion forum was conducted to gain international perspectives about use of the internet in primary care. The second part of this chapter details the research process, firstly by discussing the study setting, sampling and recruitment. This section is followed by a full justification of the design of the research instruments and description of the data collection strategies. A description and rationale is also presented on the ways in which each of the data sets were analysed. This chapter concludes with a discussion of the ethical issues encountered during this study.

3.2 Research design

The research design for this study was selected to address the nature and context of the research question. A variety of methods were appraised for their appropriateness in meeting this aim. A starting point for this study was the need to investigate the ways in which primary care patients use health information and then specifically how they use it in the primary care setting. Following this, a more detailed investigation of use was needed to explore the potential implications for patient-centred care. Given that these two issues address different perspectives, it was necessary to design a study that used quantitative and qualitative approaches.

The rationale for mixed method approach is well supported as it offers the opportunity to investigate something with breadth and depth. Langhout (2003) captures these sentiments:

> '....quantitative methods extend and inform....qualitative methods, just as....qualitative methods extend and inform....quantitative methods..... the quantitative and qualitative methods...work reciprocally to extend and inform each other' (p 229).

The study was carried out in three distinct phases, each addressing different objectives of the research. Figure 3.1 illustrates the complete project which spanned 38 months.

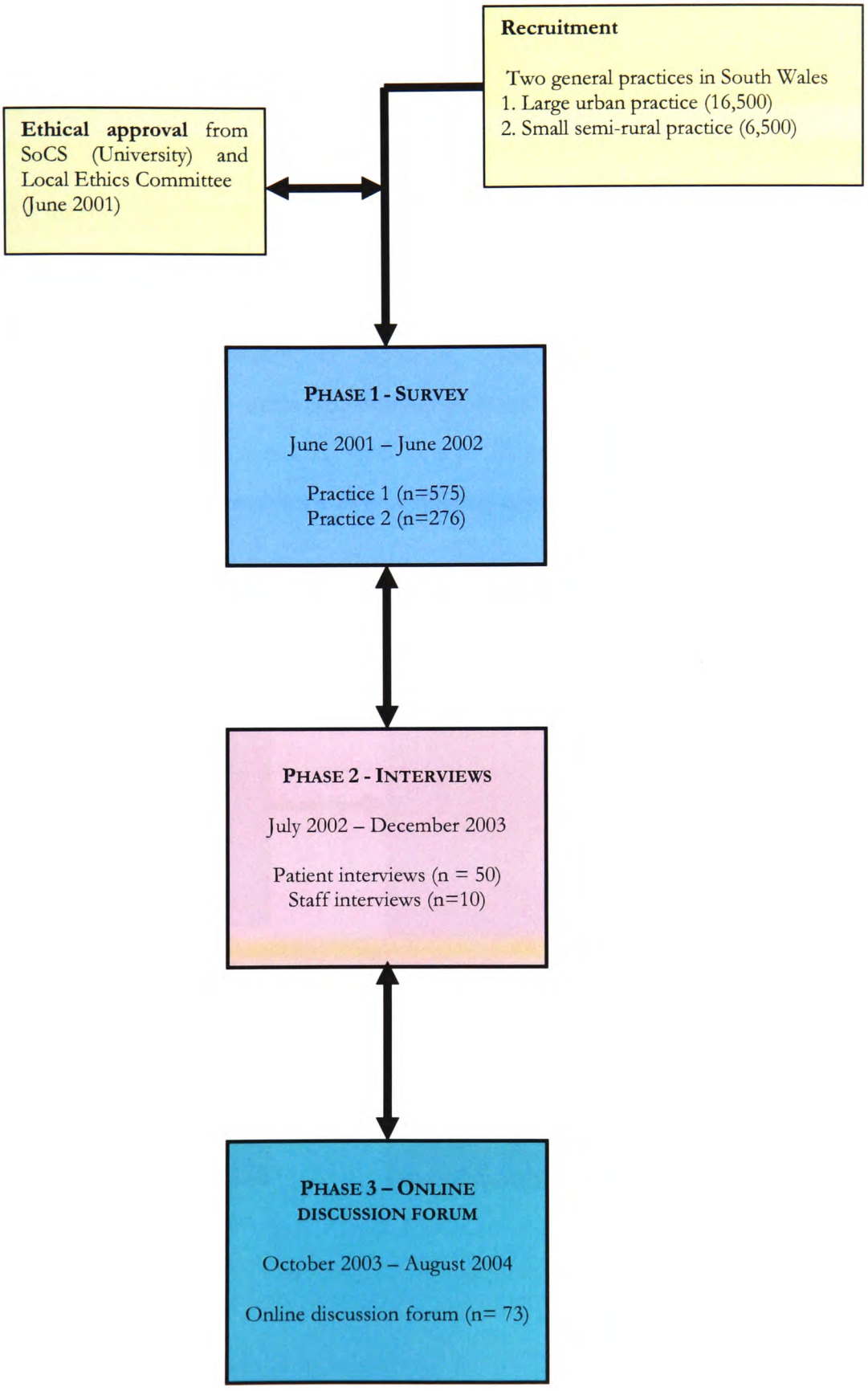
3.2.1 Phase 1 – Survey

Investigating the use of information sources warranted a descriptive approach in the form of a survey design. Surveys are inherently a quantitative means of describing the occurrence or frequency of particular phenomena. Babbie (1992) describes surveys as:

> '...probably the best method available to the social scientist interested in collecting original data for describing a population too large to observe directly' (p 262).

A survey provided an ideal means to establish the prevailing use of the internet and other health information sources in a large population. In addition, it provided structured responses about the reasons for patients' use and non-use of the internet for health information. A survey design offered a quick and convenient way of collecting quantitative data.

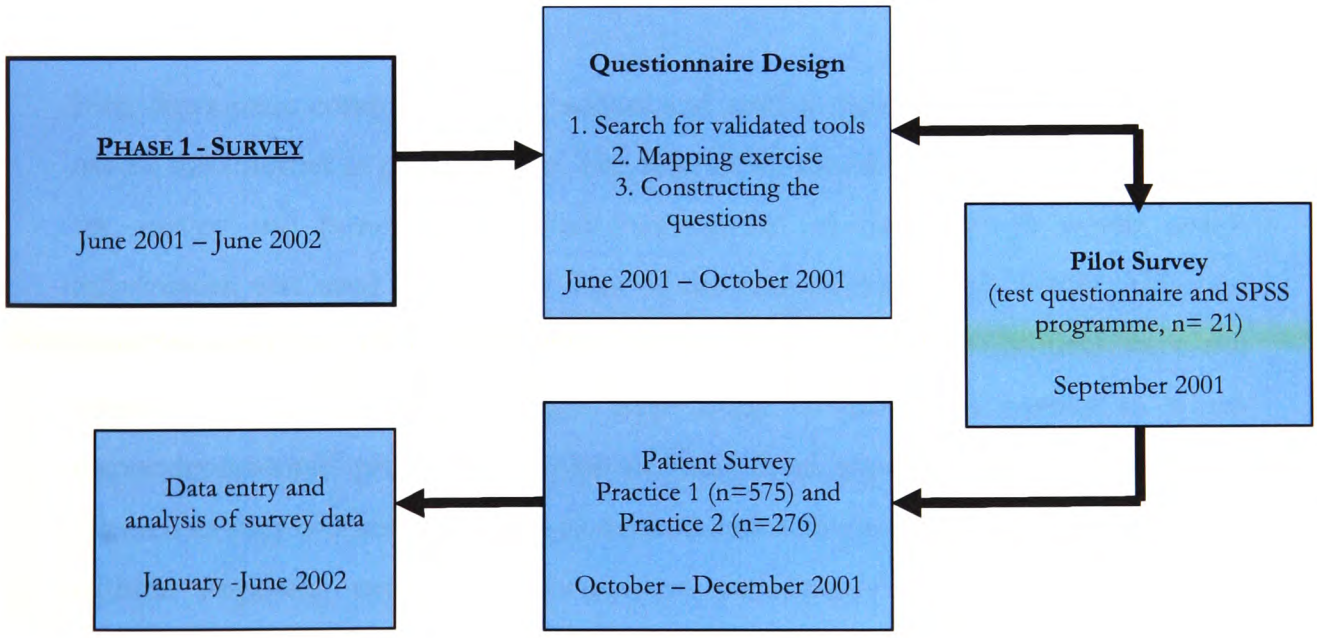
Figure 3.1 Research design



The previous chapter highlighted that the digital divide continues to prevail. One component of this project was to examine the impact of socio-economic status on the use of health information sources. A survey was therefore an appropriate way of comparing information from respondents with different socio-economic characteristics.

To ensure that the survey was robust, careful consideration was given to the key features of the design, ultimately aiming to provide a description of a representative sample (Jackson and Furnham, 2000). Sampling strategies are therefore a central feature of this research. In addition, a well designed questionnaire must be administered in the most appropriate way to maximize response and completion rates. Figure 3.2 provides an overview of Phase 1. Issues of questionnaire design, administration and analysis will be explored later in this chapter.

Figure 3.2 Phase 1 - Survey

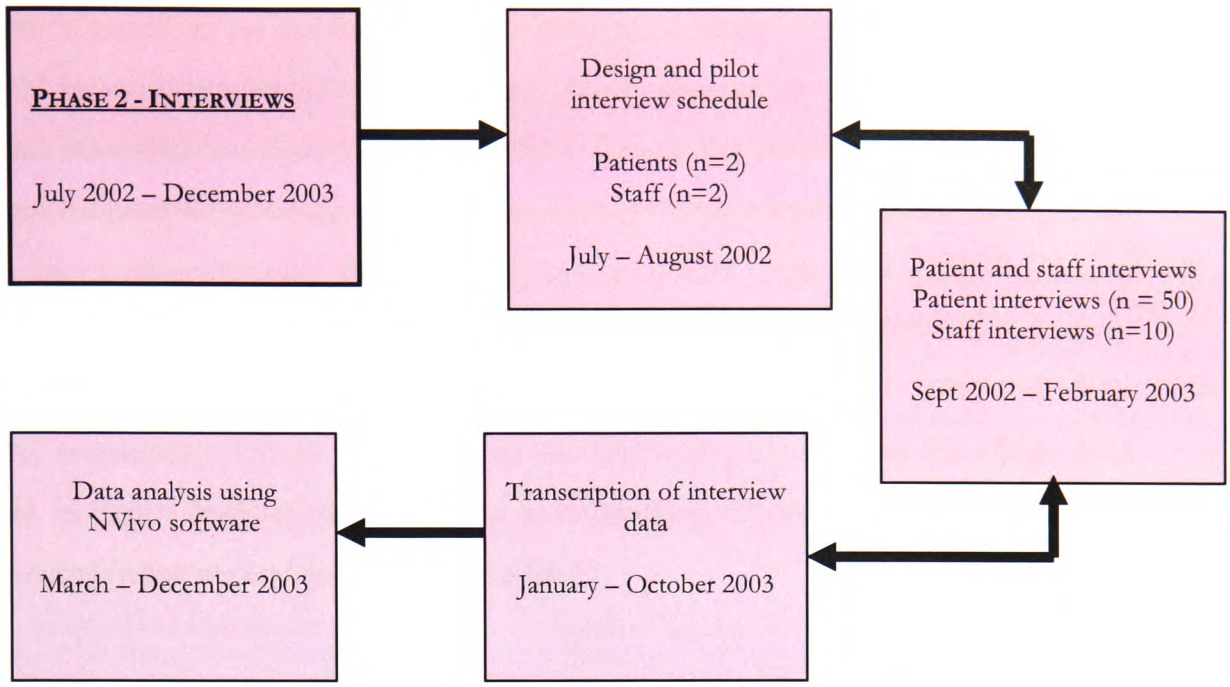


3.2.2 Phase 2 – Interviews

The second phase of the research aimed to gain a more detailed perspective about patients' use of the internet using a more interpretative approach. A qualitative design was selected to gain a greater understanding of patient experiences of using health information in different ways. Qualitative approaches offer a way of exploring the social aspects of our world. The nature of these issues is likely to result in a variety of perspectives, which does not produce one definitive answer to the research question (Mason, 2002). Although many of these issues are quite broad, qualitative research can still provide a rigorous design, which is more than a mere category for anything that is *not* quantitative. The use of qualitative methods is currently limited in the study of consumer e-health. To date, research has focused on quantifying internet use by professionals and patients, rather than exploring how the internet is used and perceptions of such use. A qualitative method therefore provided an opportunity to conduct a unique and detailed exploration into the role of the internet as an information source.

Interviews were conducted with patients and staff to gain their perspectives about use of the internet in primary care. The interviews aimed to build on the data from the survey and provide a detailed investigation of the ways in which health information was used in the daily lives of the respondents (Flick, 2002). Although direct observations of social settings (for example in patients' homes) were not captured using interviews, attempts were made to provide a context in which respondents could provide examples of their lived experiences. Interviews were selected as they offered the means to explore and understand individual perspectives without imposing restrictive structure on participants' responses (Denzin and Lincoln, 1998). They also enabled the researcher to create a relaxed atmosphere in which respondents could explore more details of their experiences (Robson, 1993). Figure 3.3 provides an overview of the processes involved in Phase 2. Design of the interview schedule, conducting the interviews and data analysis will be explored later in this chapter.

Figure 3.3 Phase 2 - Interviews



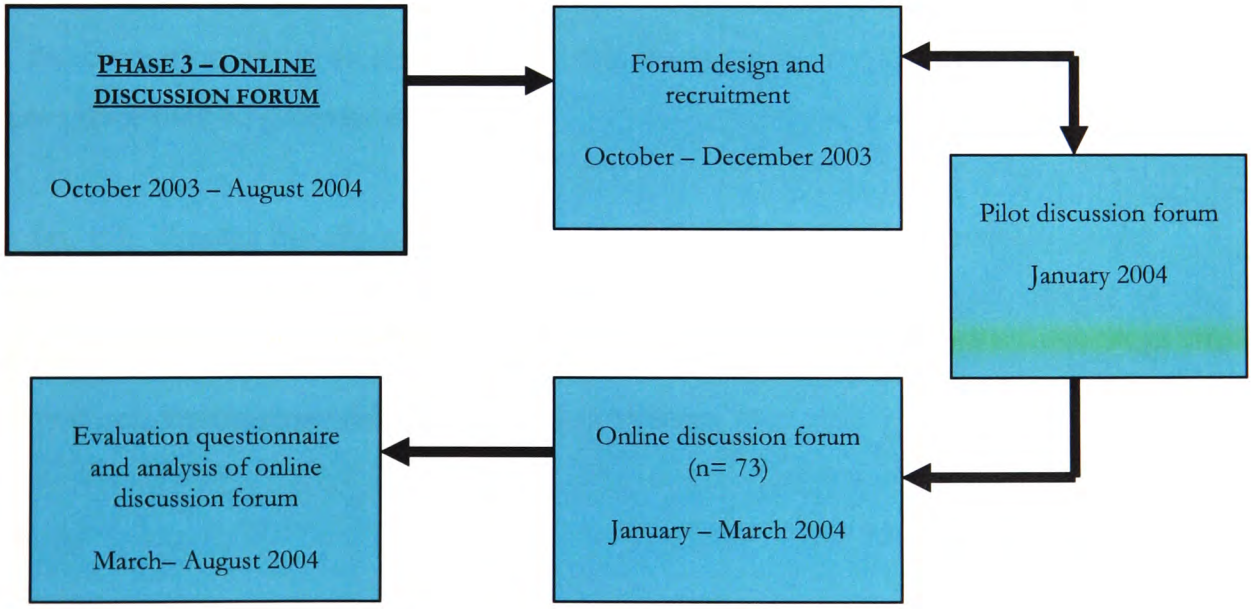
3.2.3 Phase 3 – Online discussion forum

In the final phase of data collection, an online discussion group was conducted with experts in consumer e-health and relevant disciplines. It was considered important to put the issues raised in this study into broader context by seeking views from national and international stakeholders in the field.

An online forum, designed as a bulletin board, was used to conduct a virtual discussion between a group of participants. Computer-mediated-communication (CMC) is now widely used as a means of communication, education and conferencing, with thousands of discussion groups available for people to talk about shared interests (Preece, 2000). There is a surprisingly limited amount of literature on the use of discussion fora as a means of data collection. Much of the research is based on using existing fora, rather than setting up a forum for the purpose of collecting research data. This type of data collection has generated ethical concerns about using existing discussion fora as a secondary form of data that were not

created to conduct research (Eysenbach and Till, 2001). Online fora are more commonly used for teaching or assessment purposes (Berge and Collins, 1995). Phase 3 aimed to set up a basic discussion forum using a web based format that would be easily accessible to participants. Given the nature of the topic, an online forum provided an ideal means to collect data in an innovative way. An online forum offered the possibility of including a broad range of respondents as it did not require a convenient time for all participants to attend. It was therefore feasible to include participants who were geographically distant (Murray, 1997). Respondents had access to the discussion forum at any time of the day and so could contribute when convenient. Figure 3.4 illustrates the research process used for Phase 3. A more in-depth look at the designing and running of the online forum will be presented in the second part of this chapter.

Figure 3.4 Phase 3 – Online discussion forum



A variety of other formats were available to conduct the discussion group, such as focus groups or consensus development techniques. Focus groups are an effective way of generating ideas and gaining opinions (Krueger, 1994). However, they are typically conducted with a sample size of 8-12 participants (Morgan and Krueger, 2000) and so limit the possibility of including participants from a range of

disciplines. There are also inherent difficulties in organising focus groups at a time and venue convenient to all participants (Bloor *et al.*, 2002). Recruitment issues were of particular concern in the current study as many of the targeted participants were internationally renowned in their field and so had less availability to attend a face-to-face discussion.

Consensus development techniques, such as nominal groups (Van de Ven and Delbecq, 1972) and the Delphi technique (Linestone & Turoff, 1995) were also considered. Nominal groups were originally developed to overcome problems associated with group dynamics such as dominant personalities. The discussion is controlled and is only facilitated by the researcher towards the end of the group process (Gallagher *et al.*, 1993). Alternatively, a unique feature about the Delphi process is that there is no collaboration or interaction between the experts, as the panel does not meet (Mead and Moseley, 2001). Advantages of this technique include an avoidance of social pressures of the group; however there is no opportunity for social interaction to discuss the issues from different perspectives. Although these approaches can be useful for consensus development, the purpose of the discussion group in the current study was to offer a means of exchanging ideas rather than to generate consensus.

So far, this chapter has discussed the broad methodological issues relevant to this thesis and outlined the project as a whole. The following sections provide details of the research process including the study setting, sampling and recruitment; design of the research instruments; data collection and analysis.

3.3 Study setting, sampling and recruitment

Selecting the setting to carry out the study is an important part of the research process. Achieving representativeness is a fundamental concern so that the findings can be applied more broadly to a variety of settings. Contacting health related websites would have provided contact with health internet users. However, this study focuses on the views of consumers and health professionals. The decision to sample patients from general practice was made as it enabled a comparison of the views of patients and health professionals about patients' use of health information from the internet in this locality. It also offered an insight into the role of patient health information in a primary care context. Chapter Two highlights the difficulty of addressing the health information needs of patients within the constraints of general practice (p 57). In general, Welsh consumers have a similar profile to those throughout the UK and so Wales offered an appropriate study setting. Internet access is lower in Wales than the rest of the UK offering an opportunity to investigate the digital divide. It is acknowledged that there may be regional differences in health policy throughout the UK, however, in general patients' experience of primary care services are comparable.

To obtain the views of patients and health professionals, two practices were recruited in South Wales based on the rating they received from the Welsh Index of Multiple Deprivation (National Assembly for Wales, 2000). This Index provides ratings for each region of Wales according to the level of deprivation in the area. The WIMD replaced the Welsh Index of Socio-Economic Conditions (1991) which was based on 8 ward-level indicators. This was originally developed to aid decision-making in distinguishing urban regeneration funds and therefore did not portray urban and rural deprivation. The new index is a more representative measure of deprivation as it includes income, employment, health, education, housing, and access to services. Each geographical area is given a rating according to these measures, which collectively provide the Index. The Index ranges from 1 (most deprived) to 865 (least deprived). At the time of the current study each practice was graded at opposite ends of the Index. Practice 1 was categorised as 826 making it

one of the most affluent areas of Wales. In contrast Practice 2 was graded at number 11 on the index indicating one of the most deprived areas of Wales. The decision to select practices with different levels of deprivation was influenced by the research objective which aimed to examine any differences according to socio-economic status. Chapter Two highlights that internet use is often social class-specific and therefore these very different practices were selected to take account of any potential socio-economic differences in geographical areas (p 29). Appendix 3 provides a more detailed description of each practice.

3.3.1 Survey sample selection

The study sample in Phase 1 comprised adult patients aged 18+ attending the practice surgery. This strategy entailed the use of a non-probability convenience sample as patients were only surveyed if they attended the practice, and so all patients (aged 18+) did not have an equal or known chance of being selected. The sample differed from one drawn from a practice list and this may be perceived by some as a limitation of the study. To minimise this limitation and gain a broadly representative sample of each practice population, patients were approached at all possible times of attendance to the surgery, including weekends. It was not possible to use a random sample as patient practice records were not accessible to the researcher. The lack of availability was due to ethical concerns about accessing patient details without prior consent, and the need for extensive clerical assistance from practice staff in retrieving these data. In addition, a random selection of patients from a practice list would not have guaranteed the inclusion of patients attending general practice which was of primary concern to this study. Ease of accessibility to the study population was a major advantage of using the approach adopted in this study.

A sample size of 260 from each practice detected a difference of 15% in internet access at 95% level of significance between the two practices with a power of 0.95%. Table 3.1 illustrates that the first practice is over twice the size of Practice 2. Therefore, in order to keep the samples proportional to the size of the practice

populations, the sample for Practice 1 was increased to 540. This resulted in a target sample of 800 for the total population.

Details of the actual representativeness of the sample are presented in Chapter Four (pp 95 - 101).

Table 3.1: The survey sample

Practice ID	Practice Population	Potential population (Aged 18+)	Sample (5% of population)	Survey response rate
Practice 1	13,500	10,800	540	84%
Practice 2	6,500	5,200	260	72%
Total	20,000	16,000	800	79%

Patients were excluded if they were unwell or appeared anxious or distressed. Patients were also excluded if they were not registered with the practice, for example if they were accompanying a friend or relative for an appointment. Twenty-five patients were excluded as a result of these exclusion criteria. Full details of non-respondents are detailed in Chapter Four (pp 101 – 103).

3.3.2 Interview recruitment and sampling

Patients who completed the survey were asked to indicate whether they were interested in taking part in an interview at a later date. Contacting survey respondents randomly for recruitment to the interviews could have resulted in a high number of refusals before the desired sample size was obtained. A volunteer sample therefore identified willing respondents with prior knowledge of their belonging to the desired surgery. Further details about the representativeness of the volunteer sample are provided in Chapter 4.

Patients recorded their contact details at the end of the questionnaire which stated that they would be contacted in the next few months. A total of 170 (20%) patients agreed to be interviewed by recording their contact details on the questionnaire. Interview volunteers were representative of the survey sample so that both Phase 1

and Phase 2 collected data that was representative of the practice populations and their localities in terms of gender, age and deprivation scores. Patients were subsequently contacted by telephone or post to arrange an interview at their surgery. The focus of the interviews was to explore further the use of health information, in particular the internet. It was decided that a sample of 50 patients would be appropriate for interview. This decision was based firstly on the fact that it would provide an adequate number to explore the issues to saturation (Denzin and Lincoln, 1998) but it was also a manageable size in terms of the time factor for data collection and analysis. The findings from the survey were used to ensure that where possible the interviewees were representative of the survey respondents. Three age groups were identified as a result of the survey analysis. The age bands were selected as a result of the pattern of internet access by age which emerged from the analysis (Table 4.18, p 117). Two thirds of those aged 54 or under used the internet compared to 36% of those aged 55-65 and 19% of those aged 75+. The age bands were therefore condensed into these 3 categories. The interviews also included non-users of the internet to provide a comparison with other health information sources. Table 3.2 illustrates the potential interview sample, stratified into 6 categories according to internet access and age.

Table 3.2: Interviewees broken down by internet access and age

Age (yrs)	Internet users	Non-users	Total
18-54	66	42	108
55-64	14	18	32
65+	9	21	30
Total	89	81	170

Based on a sample of 50 patients the total required for each category was calculated using the following equation:

$$\text{Number of patients per category} = \frac{n \times 50}{170}$$

n = number of patients in each category in above table 3.2

Table 3.3 displays the number of patients for selection by category. The minimum number in any of the categories was 3 patients which was slightly lower than desired.[1] The sample would have needed to be increased to 67 in order to raise this figure to 4 patients. This sample size was not considered to be a manageable number of interviews to conduct and analyse and so the sample size remained at 50.

Table 3.3: Interview sample

Age (yrs)	Internet users	Non-users	Total
18-54	19	13	32
55-64	4	5	9
65+	3	6	9
Total	26	24	50

The required number from each sub-category was randomly selected from the population of interviewees. Table 3.4 shows the distribution of patients randomly selected according to each practice.

Table 3.4: Interview sample by practice

Age (yrs)	Internet users		Non-users		Total
	P*1	P2	P1	P2	
18-54	13	6	6	7	32
55-64	4	0	3	2	9
65+	1	2	4	2	9
Total	18	8	13	11	50

**(P = practice)*

It was intended that the survey results would, in part, inform the interview schedule. The interviews were therefore carried out after the survey analysis. To maintain

[1] χ^2 tests - the expected number of readings in each cell should be 5 or more, however tests for statistical significance were not applied to the interview data.

interest in the study all potential interviewees were written to at a mid-point between the survey and interview informing them of an approximate time-scale of when the interviews would be carried out (see Appendix 4). Subsequently, patients who were randomly selected were contacted by telephone (n=48) or post (n=2). Although written information about the interview was provided at the survey, the information was reiterated to patients during the recruitment phone call. Patients were advised that if they were in agreement, the interview would be tape-recorded. Participants were reassured that all information would be confidential and anonymous. All willing participants agreed to be tape-recorded (Appendix 5). If a patient from the initial selection was not willing or unable to attend for interview a suitable replacement fulfilling the same criteria from the relevant sub-category was selected. In some cases an exact match was not available and so a match with the most similar characteristics (age and internet use) was included.

All staff from each practice were approached for interview. An information sheet was provided for each staff member (Appendix 6) in which they were assured that participation was voluntary and that all information would be anonymous and confidential. Staff were asked to indicate whether they used the internet for health information. A selection of internet users and non-users were interviewed. Recruitment was ultimately determined on the basis of staff interest in the study and the capacity to set up a date and time convenient for the researcher and potential interviewee. Table 3.5 lists the roles of staff approached for interview.

Table 3.5: Profile of staff interviews

Practice	GP	Nurse	Receptionist	Practice manager	Total
1	2	2	1	1	6
2	2	2	1	1	6
Total	4	4	2	2	12

3.3.3 Recruiting participants for the discussion forum

Representatives from a variety of disciplines were selected according to their experience and relevance to consumer e-health. These included primary health care professionals, academics, health service management, policy, consumerism and health technologies. A pre-requisite was that all potential respondents had access to the internet and some technical proficiency in order to use the discussion forum. Due to the nature of the topic, which focuses on use of the internet, the target audience were all likely to have experience of using the internet. The interactive style of the discussion forum also provided a useful half-way measure between verbal and written formats (Salmon, 2003). This format also minimised the pressure felt by respondents who may be discouraged from providing more formalised verbal or written contributions.

A list of named key informants was devised from the literature and attendance at conferences. A target sample of 60 participants was deemed appropriate to gain sufficient discussion from a range of participants (Salmon, 2003). Each identified group member was contacted by e-mail/letter to take part in the forum (Appendix 7).

The participant information included details on the purpose of the forum, why they had been selected and contact information about how to get involved. Participants were asked to nominate a suitable colleague if they were unable to take part. A flyer was also distributed at a presentation delivered by the researcher at MedInfo 2003 (Dolan *et al.*, 2004), a widely attended international conference with the theme of consumer use of the internet. The forum was also publicised on relevant discussion lists and websites to generate further interest. Participants were excluded if they were not English-speaking. Some respondents requested direct access to the web-link so they could pass this on to fellow colleagues. Direct access in this way was declined to ensure that users accessing the forum fulfilled the inclusion criteria.

Table 3.6 provides details of the final sample registered for the discussion forum by discipline. In cases where a person could be classified in more than one discipline, their main role was used.

Table 3.6: Forum sample by discipline

Discipline	% (n)
Academia	51 (37)
Health care professionals	23 (17)
Health technologies	8 (6)
Politics/NHS management	8 (6)
Consumerism	7 (5)
Other	3 (2)
Total	100 (73)

The other category comprised one health journalist and one manager from private health care. Although they did not represent the five pre-determined categories, they were considered relevant to the discussion and so were included in the sample.

Health care professionals and academics were considered to be the largest stakeholders and so comprised a greater proportion of the target sample. There was a fairly even distribution of gender, with 39 (53%) women and 34 (47%) men. Table 3.7 shows the distribution according to country of origin.

Table 3.7: Forum sample by country of origin

Country	% (n)
UK	62 (45)
USA	15 (11)
Finland	4 (3)
Australia	3 (2)
Canada	3 (2)
Germany	3 (2)
India	3 (2)
Netherlands	3 (2)
France	1 (1)
Israel	1 (1)
Italy	1 (1)
Portugal	1 (1)
Total	100 (73)

It was decided not to include patients in the discussion as their views were addressed sufficiently in Phases 1 and 2. Perspectives were sought from the context of primary care in the NHS, so many of the named respondents were from the UK. However, the remaining respondents were able to offer alternative perspectives, particularly from Europe and the United States.

3.4 Designing the research instruments

This section illustrates the process of designing the research tools used in each of the three phases. A detailed justification of the selection and design of the instruments used in the empirical research is included.

3.4.1 Questionnaire design

Consumer e-health is a relatively new area of research. As a result, no validated questionnaires were available for use in this study. During a search for data collection tools the researcher discovered many validated tools available to measure heath related areas (Bowling, 1995; Johnston *et al.*, 1995). However, with the exception of the Health Value Scale (p 79), none were deemed relevant for use in this study.

In an attempt to establish the main components of the questionnaire, the researcher conducted a conceptual mapping exercise (incorporating themes from existing literature) in which the aims and objectives of the research project were categorised into themes and sub themes (see Appendix 8). This process was carried out to ensure that questions in the survey were appropriate and necessary to address the areas of interest. It was soon realised that the questionnaire would not be suitable to examine some of the more exploratory questions, such as patient views and experiences of information seeking. These issues were therefore incorporated into the interviews in Phase 2. In addition, a small number of questionnaires used in

studies identified in the literature were found which covered some topics of interest to the researcher (Cyberdialogue Internet Access Survey, 2000; Fox and Rainie, 2000; Health on the Net Foundation, 2000). These questionnaires mainly investigated general internet use and health internet use and so informed the questionnaire design. They were however less relevant for the development of questions about non-users.

Oppenheim (2000) highlights the importance of question wording and where possible suggests avoiding long and complex questions, the use of jargon, double-barreled or leading questions. The questions were kept as simple as possible for ease of communication and response efficiency. However it was necessary to use some filter questions in order to distinguish between internet users and non-users. The researcher was available to clarify any questions and so using this format was not considered a problem. The questionnaire comprised 19 closed questions which focused on the following four areas:

- Use of health information sources (questions 1 - 5)
- Use of the internet (questions 6 - 12)
- Health value scale (question 13)
- Demographics (questions 14 - 19)

Use of health information sources

Patients were firstly given a list of 16 sources. They were asked to indicate by a tick box whether they had used each source for information about an illness, or for general health information, during the previous six months. Patients may use different sources for specific information than for general health information and so the format of this question enabled the researcher to identify any differences. Patients were also asked to identify the source from the list which they used most frequently and which source they preferred most. This question provided useful information on whether the source they use most frequently is actually their preferred source. In some cases although patients have a preference for a particular

source, they may have difficulties accessing this source. This question could be used as an identifier to determine whether the participants mainly access information about an illness or for general health information.

Internet use

A series of questions focused on general use of the internet. The concept of internet 'access' versus internet 'use' was an important consideration as the terms have different meanings. The use of terminology varies in internet surveys and so a standardised guide was not available. It was decided to firstly focus on access to the internet, as some patients might have access to the internet but not actually use it. The next question focused on where patients used the internet. Patients also recorded where and how long they had used the internet from a list of options. This question was useful in order to measure whether there were any differences in length of use between practice patients and also to determine whether length of use would affect how patients used the internet and what they thought of it.

Questions were also included to find out more about whether patients actually use the internet for health information, and if so, what they do with the information; specifically whether patients bring health information from the internet into consultations. They were also asked to indicate how a number of statements about use of the internet related to their views. This information would then to be used to identify perceived advantages or disadvantages of using the internet during a consultation. The statements were devised as a result of themes which emerged from the literature.

Although some patients may use the internet they do not necessarily use it for health. Patients were therefore asked to record possible reasons for not using the internet for health. General internet surveys such as a quarterly internet survey produced by the Office of National Statistics (2002b) provided some assistance in constructing this question. Although these surveys do not focus on health, some of the reasons for general non-use of the internet could be applicable to this study. Consulting existing surveys in this way enhanced the content validity of the questionnaire.

Health value scale

The Health Value Scale (Lau *et al.*, 1986) was identified and included as part of the questionnaire to measure the value which patients placed on their health. This validated psychometric scale would provide a variable to gauge motivations for accessing health information (see Appendix 9). The scale consists of four statements each of which the respondent has to rate from a scale of 1 (strongly agree) to 7 (strongly disagree). The patient can achieve a minimum score of 4 and a maximum score of 28. Statements two and four are negative and so are scored in the opposite direction 7 (strongly agree) to 1 (strongly disagree). The higher the score, the higher the health value. The authors of this tool believe that having a high value of health influences the degree to which people perform health related behaviour. For the current study the scale was used to determine whether health value influenced the ways in which people in the different practices accessed sources of health information.

Demographic data

The final questions related to demographic information. The variables of age and gender were included to investigate any differences in the use of health information according to these factors. The remaining questions served as measures of socio-economic status. Although the practices were located in different areas of deprivation this did not provide any indication at an individual level. The employment and education data of individual patients were included to represent the socio-economic status of individual patients. Validated surveys were consulted for details about methods of collecting demographic data. Details from the 2001 Census questionnaire informed the selection of the demographic questions. The Census used the National Statistics Socio-economic Classification (NS-SEC) which replaced social class categories based on occupation (ONS, 2001a).

Piloting the questionnaire

The questionnaire was piloted to test its reliability and validity. This included examining the format and structure of the questionnaire and aimed to determine whether the respondents understood the questions correctly. Firstly, it was distributed to 12 nursing students studying at the University in which the researcher was based. These students would not be representative of the patients in the main study but could provide some useful comments about completing the questionnaire. A few minor changes were made before the second (main) stage of the pilot, for example a student category was added to question 16. The revised questionnaire was distributed to patients at a GP surgery in South Wales (ranked 46 on the index of multiple deprivation) which was not related to the study. The method of distribution involved the researcher approaching patients in the waiting room of the practice. Following an introduction from the researcher and brief summary of the project, patients were invited to complete the questionnaire. They were given an information sheet and a pen (if required) to complete the questionnaire. Information on the questionnaire indicated that on completion patients should return it to the researcher. Responses were received from 21 patients in the surgery.

The responses were analysed using SPSS Version 12 (Statistical Package for the Social Sciences). The pilot exercise confirmed that the questionnaire was easy to complete and that respondents did not have difficulties with any of the questions. It also confirmed that the distribution method was effective as it provided a response rate of 80%. One of the concerns of the survey was the inclusion of filter questions; however these questions did not appear to cause any confusion and all patients completed the appropriate questions. Another concern was whether patients would record their exact age and the possibility that a banded age category would be more appropriate to record age. Although the questionnaire was anonymous, patients had to return it to the researcher and so may not have wished to record their true age. As detailed earlier this is a disadvantage of having the researcher present. In the pilot study all patients recorded their age so this question was not amended. Some

patients recorded more than one response to question two. In order to ensure that patients only listed one source the word 'one' detailed in the question was changed to upper case to provide further emphasis. It was decided that in the main survey if more than one response was recorded then the first answer was taken as the one used most often.

To increase anonymity, it was decided to provide a closed box in which patients could return their questionnaires. None of the patients asked for any assistance in completing the questionnaire so it could be assumed that the instructions were clear and easy to follow. The questionnaire took about five minutes to complete and so was not lengthy. The pilot revealed that patients found the questionnaire fairly easy to complete and so self-administration was confirmed as the most suitable option. A copy of the final questionnaire can be found in Appendix 10.

3.4.2 Interview schedule

A semi-structured interview schedule was devised featuring principal questions of interest to the researcher. Developing an appropriate interview guide is a critical process, which has been given limited attention in the literature about conducting interviews (Gillham, 2000). Structured questions were developed which focussed on the following areas:

- Use of health information sources;
- Reasons for use of health information sources;
- Ways in which the internet is used for health;
- Use of the internet during primary care consultations.

A semi-structured interview allowed the researcher to probe further into responses of interest and to assist mutual understanding of questions and responses. Respondents also had the opportunity to introduce issues which they viewed as important for discussion. Appendix 11 provides details of the schedules used during the interviews. The schedules were constructed according to the research

objectives, themes from the literature and areas identified for further exploration following the survey. The patient interview schedule was revised for staff to include perspectives about their own use of information sources and their perceptions of patients' use of health information. The schedules were tested by conducting interviews with 2 patients and 2 staff members from the surgery selected for the pilot of the survey. The pilot interviews produced fruitful and relevant discussions confirming that a semi-structured interview was a suitable method of data collection. Minor amendments were made to the schedule following the pilot interviews. These changes included rephrasing the introductory questions to a more open-ended style to offer respondents more scope to provide their own perspective.

3.4.3 Design of an online discussion forum

Two options were explored when considering the development of the discussion forum. Firstly, using an existing forum such as Blackboard, or secondly building a new discussion forum using web development software. Existing fora were not available due to licensing constraints. Therefore, PhPBB (PhP Bulletin Board), an open source software, was selected to develop the discussion forum. This software is widely used on discussion fora and has been freely available since June 2000; further details can be found at http://www.phpbb.com. The greatest factor when selecting the software was that it was user friendly. PhP is well-established and offers a tried and tested format for discussion fora. Formatting options in open source software vary. An advantage of PhP was that a variety of formatting options were available to customise the forum, for example by using the University logo. Ease of moderating the forum was also an important concern for the researcher. When developing the forum, the researcher was given relevant advice and assistance by staff at the university information systems and e-learning services.

An online forum was more cost effective than a face-to face discussion. Participants logged on using access to their own computer and internet connection and so may have incurred a connection fee, dependent on computer use at work or at home and their on-line tariff. The majority of costs were associated with the researcher's time

for setting up, moderating and analysing the discussion forum. The costings were consistent with other examples of e-fora such as Salmon (2003) who conducted an educational discussion forum which was estimated at a quarter of the cost of a face-to-face discussion forum.

A major factor when considering an online forum was the ability to encourage participation. Salmon (2003) describes a series of stages that participants may go through, that include access, motivation and online socialisation. Some participants may be reluctant to post and may 'lurk', by reading messages without replying, before they feel comfortable in posting messages (Jones S, 1999). A discussion without face-to-face contact may be a concern for some as this could depersonalise the discussion. There are also limitations due to the absence of visual and non-verbal cues (Sweet, 2001). However, it may also be viewed as a strength as it facilitates freedom of expression (Roberts *et al.*, 1997) cited by Selwyn and Robson, 1998).

Even with the anonymity of discussion fora, a hierarchy can develop in which some respondents dominate the discussion forum with their ideas. Parallels can be drawn with the group dynamics in face-to-face contact, but in online discussions respondents can start a new thread or chose to withdraw from a discussion. Such difficulties could be managed by the moderator who could intervene if a person was dominating the forum in a detrimental way.

The forum was placed on a dedicated secure research server at the university, which has the capacity to store large data sets. Access to the server, including the online forum, was password protected to ensure confidentiality. A test forum was set up and then customized, which involved changes to the overall format of the site. Following this initial development, the online forum was piloted with colleagues in the researcher's department. An information sheet was e-mailed to participants with a link to the forum and details about how to register. The researcher set up an initial thread to start the discussion. Colleagues engaged in a planned discussion about using the forum for approximately 30 minutes. The forum was left open for two weeks for discussions about using an online forum. This pilot study provided

sufficient information to test out all of the forum functions. Following the pilot, a number of queries were raised, which mainly related to technical issues and formatting. A series of changes were therefore made, the most important being the registration process. The researcher decided to register all users in advance, by sending them their username and password. This option was selected over self-registration for two reasons. Firstly, to avoid difficulties in self-registration encountered during the pilot study, and secondly to provide the moderator with greater control over who registered on the forum. The forum was then tested again to confirm the final settings.

The discussion forum used asynchronous communication in which the contributions were not typed in real-time, but were available once the contributor submitted a completed response. This format therefore gave participants the opportunity to think about the discussion thread and to formulate a reply after they had processed their ideas. Participants could also raise questions at any time without feeling the need to wait their turn, which can be a constraint when conducting face-to-face discussions (Robson, 1999). The effect of the researcher was also minimised, as although the researcher engaged in selective moderation, participants were free to guide the discussion with their own ideas. The discussion focussed on the following areas:

- the ways in which patients can be facilitated in their use of health information from the internet;
- the role of health care professionals in responding to patients with internet information;
- future developments in relation to the use of electronic sources of information for patients in primary care.

3.5 Data collection

3.5.1 Administering the questionnaire

Survey data can be gathered by using an interview administered or self-administered questionnaire. It was important to decide the most appropriate way to administer the questionnaire in order to maximise the response rate and reduce potential bias from the researcher. Table 3.8 illustrates some of the advantages and disadvantages of the approaches available to the researcher. These factors were used to select the most appropriate method to administer the questionnaire in the current study. Patient contact details were not available to the researcher which excluded telephone and postal surveys. The next decision was whether the questionnaire would be interview administered or self-completion.

Table 3.8: Advantages and disadvantages of questionnaire administration

	Face-to-face interviews	Telephone interviews	Postal questionnaire
Response rates	Moderate/high	Moderate	Low/moderate
Response bias	High	Moderate	Moderate
Interviewer bias	High	Moderate	Low
Cost	High	Moderate	Low
Data collection period	Long	Short	Long
Long questionnaires	Good	Moderate	Poor/moderate
Complex questions	Good	Moderate	Moderate/poor
Filter questions	Good	Good	Moderate/poor
Open-ended questions	Good	Good	Poor

Adapted from McColl et al., 2001

Table 3.8 shows that interview administration provides high response rates and offers the greatest flexibility in questionnaire design. As the researcher intended to approach all patients attending the surgery at a particular time, an interview survey was not realistic. If the researcher was completing the survey with one respondent, they would be unable to approach other patients entering the surgery. It would also be necessary to administer the questionnaire in a private area to ensure patient confidentiality. The survey was fairly brief and simple to complete and so self-completion was a suitable method. Considering the topic area, an internet survey

could offer an ideal medium to collect the survey data; however, this would only include internet users. Adopting an internet survey could put the sample at risk of selection bias, which would reduce the generalisability of the results (Eysenbach & Wyatt, 2002). Patients were therefore recruited using face-to-face contact using a self-completion questionnaire. This strategy provided a useful blend of approaches that addressed many of the limitations presented in Table 3.8.

All adult patients attending appointments were approached in the waiting room of each surgery to complete the questionnaire. A verbal introduction was provided by the researcher which included a summary of the research study. A more detailed written patient information sheet (see Appendix 5) was attached to the front of the questionnaire for the patient to read. If the patient agreed, they were given the questionnaire for self-completion. Patients were given the opportunity to withdraw from the survey if on further reflection they did not wish to take part. A research stand was set up in reception which housed a box in which patients could place the completed questionnaires. This method ensured patient anonymity as the questionnaires could not be linked to an individual patient.

3.5.2 Conducting the interviews

Patients and staff were interviewed in each of the respective practices. The interviews were conducted in consulting rooms that were available. Conducting them in a primary care setting offered an ideal means of exploring patient and staff perspectives in the 'real-life setting' in the context that primary care interactions occur (Gillham, 2000). The interviews were semi-structured and ranged from 25 minutes to 1 hour 20 minutes in length. The average time of interviews was approximately 45 minutes. This duration provided adequate time to explore patient and staff experiences and gain a more in-depth insight into their views about using the internet in primary care. A face-to-face interview enabled the researcher to identify any non-verbal cues which helped to further explain some of the views expressed by the participants and could also be used to anticipate the *'social dynamics of interviewing'* (Mason, 2002).

3.5.3 Managing an online discussion forum

The online forum was launched on the 20th January 2004. The sample (n=73) were contacted by e-mail with the URL (http://resnt1.isd.glam.ac.uk/phpbb2), and given username and password details needed to log on to the forum. Although most participants were likely to be active users of technology, assumptions were not made (Clark, 2000). Clear instructions were given to all participants in the form of a frequently asked questions guide (devised by PhP) about how to use the discussion forum.

Following the initial thread, the moderator (username supervisor) commented where necessary, but endeavoured to maintain a professional distance from the forum. A new thread from a pre-determined list of threads devised by the moderator was added on a weekly basis to stimulate further discussion. The planned duration of the forum was 4-6 weeks, depending on participant activity. It was felt that this timescale would allow suitable time for discussions to develop as most of the activity in online fora occur during the first two weeks (Murray, 1997). Appendix 12 provides a screen-shot of the discussion forum. An electronic feedback questionnaire (Appendix 13) was sent out one week after the forum closed to gain information about use and non-use of the forum. The questionnaire included questions about using the forum and opinions about the future of consumer e-health.

3.6 Data analysis

A variety of data were obtained during data collection comprising numerical and textual formats. Each data set was processed and analysed using appropriate techniques consistent with the form of the data.

3.6.1 Survey analysis

Data from the survey were analysed using SPSS. All questions were pre-coded using a standard coding scheme, for example no=0; yes=1. Pallant (2001) describes this as a 'codebook' highlighting the importance of preparing and piloting the codebook prior to data collection. In the current study the codebook formed the basis of an SPSS programme written specifically to analyse the questionnaire. Appendix 14 provides detail of the full programme and the associated coding for the questionnaire. Writing an SPSS programme merely provides a quick and efficient method of creating a data file in SPSS ready for analysis. If the programme format had not been used the data would have been coded in the same way and the variable and value labels would have been created manually in SPSS. To test for accuracy of data entry 5% (n=40) of the questionnaires were double entered into SPSS. No errors were identified which ensured that data entry was likely to be accurate.

The analysis mainly comprised descriptive analyses such as frequencies, and associations. Chi-square tests were used to investigate significant associations in the categorical data. Pearson's Correlation was used to test the strength of the relationship between variables.

3.6.2 Analysing the interview data

The interview data were transcribed verbatim and prepared for export to NVivo for analysis. Six interviews (10%) were randomly selected for independent checks on the accuracy of the transcription. Each volunteer was given a copy of the taped interview and the associated printed transcript. They were asked to highlight any discrepancies between the tape and transcript. This information was recorded in the relevant place on the transcript. Discrepancies were assessed to judge whether transcription was adequate, or if further checks were necessary. Errors identified were missing words like 'the/and', which did not affect the interpretation of the

transcript in any way. This check therefore served as a useful mechanism to ensure that the transcripts were reliable and further changes were not necessary.

The completed transcripts were imported into QSR NUD*IST Vivo (Non-numerical Unstructured Data* Index Searching and Theorising Vivo).[2] This computer assisted software package enables the handling of rich text, non-numerical data, allowing free editing and coding. NVivo provides a computerised method of examining text; recording how thinking has evolved in annotations or memos; coding and reviewing coded data and searching for patterns. Demographic and other quantitative data obtained from the respondents in Phase 1 were imported into NVivo allowing for comparative analyses of subgroups within the sample. The researcher developed expertise in using this package by attending a residential training course in Australia, which provided the researcher with a valuable opportunity to immerse herself in the data set.

Coding

In the early stages of coding, text was grouped into broad themes which displayed common features. Once the core themes were established, a more detailed analysis of the data resulted in the generation of sub-themes, using a form of content analysis. This type of code and retrieval process enabled the identification and retrieval of data coded under each theme. Care was taken to ensure that the data were kept in context and that the code and retrieval process did not result in data reduction. This process is captured by Tesch (1990) as stages of decontextualisation and recontextualisation of the data. Decisions about how much data to code are important to keep the context of the data. A small number of general codes may not provide an in-depth analysis, whereas a large number of codes with small segments of text assigned to them may take the data too much out of the context of the interview (Coffey & Atkinson, 1996). Attempts to strike a balance between these two types of coding were maintained by constant reference to the study objectives. During this process a project journal was used to document the thinking behind the coding strategy and record how the analysis process evolved. The NVivo package

[2] (http://www.qsr.com.au/products/nviv.html)

also provided a log of the coding process, documenting any changes or amendments to themes.

The coding structure was developed using pre-determined and newly emerging themes. The latter offered a more inductive approach as themes were generated in the context of the data. In any research study it is difficult to ignore pre-conceived ideas, however adopting a more inductive approach can minimise these biases. The selection of names for particular themes were derived from core features of the literature, key terms that respondents used and categories created by the researcher which embodied the viewpoint of respondents.

An important aspect of the analysis was to determine the concepts behind the coding and the relationships between the themes. Coffey and Atkinson (1996) provide an apt description of codes as:

> '...links between the locations in the data and sets of concepts or ideas, they are in that sense heuristic ideas' (p 27).

This description reflects the exploratory nature of coding in which the researcher searches for meaningful ideas from these data. The relationship between the themes was also examined to determine whether the coding system was justifiable. Coding was not fixed at this stage and so themes were re-named, merged or deleted as necessary. NVivo searching tools were used to determine the robustness of the coding strategy. For example, investigating the overlap between themes by conducting an intersection search between coding assigned to two different themes. Details on each stage of the coding are provided in Appendix 15.

A selection of the data (5 transcripts, 10%) were also analysed by another researcher to provide check the reliability of the data analysis (Hammersley and Atkinson, 1995). In over 80% of cases researchers agreed on the coding, and in cases of disagreement, each researcher presented their justification for the coding and subsequent agreement was reached.

The role of the researcher was also an important consideration. In the current study, all the interviews were conducted by one researcher, however the interviews were in part unstructured, so the context of each interview focused on discussions raised by the interviewee. Potential biases are not a major consideration as the aim of the interviews was to gain an insight into the experiences of each respondent, yet without adopting a standardised approach (Dey, 1995). The researcher did however record field notes about her overall impression of each interview to provide further insight into how the interview went. Key points considered were whether the researcher influenced the respondent in any way and any factors which may have influenced the discussion in particular.

3.6.3 Analysing the discussion forum and evaluation

The forum data comprised textual responses from the discussion threads (pp 176-183). Threads were downloaded from the website and converted into a rich text format for analysis. Due to the nature of the data, the threads were analysed using a narrative approach, which offered a description of how the discussion evolved, highlighting the key areas of importance raised by respondents. This approach differed slightly from the interview analysis as the forum data were analysed chronologically as the discussion (narrative) evolved. In addition, quantitative data were collated in relation to forum activity, such as frequency of browsing the website. The evaluation questionnaire provided quantitative data which were analysed using descriptive statistics. Qualitative data were also collected which were analysed using a content analysis of free text responses.

3.7 Ethical considerations

Ethics is an important feature of any research project involving people. The morality of any given action is of particular concern in social research (Babbie, 1992). It is important to consider factors which may affect the ethical standing of the research for the duration of the study. This study was conducted within an ethical framework based on the principles of informed consent, privacy and confidentiality. Prospective participants were recruited on a voluntary basis with no sanctions against withdrawal. All participants were provided with written details of the study, explaining the purpose of the study and their commitments to the project (Appendices 5 - 8). Compliance with the Data Protection Act (1998) was ensured through liaison with the University's Data Protection Officer. Ethical approval for this study was obtained from the University and the Local Research Ethics Committee in June 2001 (see Appendix 16).

At the survey stage, patients were assured that the information would be anonymous. The questionnaires were coded with a unique identification number which could not be traced to any of the respondents. On completion the questionnaires were placed in a sealed box by the respondent providing further security of anonymity. Although patients who attended for interview were not anonymous to the researcher, a code was used to replace the name of the respondent in each interview. The identification of each patient was recorded in a master identification file which was only available to the researcher. Data collected from the survey and interviews were stored in a locked filing cabinet that was only accessible to the researcher.

When attending for interview, patients were asked to report to reception on arrival at their surgery. Reception staff were therefore advised that the identity of patients taking part in the study should be kept confidential. Interviewees were assured that their name would not be linked to any of the data and that the anonymised data would only be accessed by the interviewer and University supervisor.

The identity of participants was not revealed in the online discussion forum and was only accessible to the researcher. Potential participants were given a username and password issued by the researcher. They were also given an information sheet explaining the expectations of the research. Consent was assumed from any potential participants who engaged in the discussion forum. Terms of reference were included for the duration of the forum. One of the main ethical considerations was the decision about whether anonymity would be maintained in the discussion group (Langford, 1995). Anonymity has a number of advantages as respondents are less likely to be influenced by certain responses if they are unaware of the identity of the contributor. Respondents are also less likely to be judgmental, for example according to age or gender. Although the identity of respondents was not revealed by the researcher, a few respondents chose to include their full names in the discussion. Security is also an issue for online communication; however the forum was placed on a secure server. Access was only gained by a username and password supplied by the moderator.

3.8 Conclusion

This chapter has presented an overview of the methods used in this study. It can be seen that detailed consideration was given to selecting the most appropriate design to address the aims of this study. A clear rationale has been included about decision making in the research process in respect of data collection and analysis. The following three chapters present the findings of each phase of the empirical research.

CHAPTER FOUR

SURVEY RESULTS

4.1 Introduction

The results of the survey phase are divided into two sections. The first section focuses on sample representativeness of the general practice patients with respect to this study and other studies on the wider population. This section also includes information about the response rate, non-respondents and a comparison between the two practices. The second section presents a descriptive account of the results from the questionnaire.

The questionnaire data comprised mainly categorical data, therefore necessitating the use of non-parametric statistical tests. These data were analysed with SPSS V.12 using descriptive statistics, Chi square (χ^2) tests of association and goodness of fit. In tests of statistical significance, the significance level was set at $P \leq 0.05$. Any record of p=0.00 indicates a significance level of less than 0.01.

4.2 Representativeness of the sample

This section examines the extent to which the results from the survey were representative of patients attending general practice and the wider population. Patients were selected from two general practices in South Wales, chosen according to their deprivation levels. Practice 1 is situated in a large city in one of the most affluent areas of Wales. The second practice is in a semi-rural area, which is one of the most deprived areas of Wales.

Table 4.1 shows that the questionnaire distribution produced a high overall response rate of 79% with no significant difference between practices. A total of 851 patients responded, fulfilling the sample size requirements.

Table 4.1: Response rate by practice

Practice	Total patients approached	Returns	Response rate
Practice 1	687	575	84%
Practice 2	386	276	72%
Total	1073	851	79 %

In order to account for the uneven distribution of respondents in each practice, tests on individual characteristics (e.g. gender) according to practice are conducted using percentages rather than frequencies to correct for potential bias.

4.2.1 Gender distribution

A Chi square test of goodness of fit showed a significant difference between the distribution of men and women within each practice at the 0.01 level (Practice 1 χ^2 = 71.09, df=1; Practice 2 χ^2 = 29.77, df=1). Women account for a much higher proportion of those attending general practice than men (Table 4.2).

Table 4.2: Gender distribution by practice

Gender	Practice 1 % (n)	Practice 2 % (n)	Total % (n)
Men	32 (179)	33 (91)	33 (270)
Women	68 (378)	67 (181)	67 (559)
Total*	100 (557)	100 (272)	100 (829)
χ^2 (1) Goodness of fit test	p= 0.00	p= 0.00	

** 22 missing values for gender*

These differences can be partly explained by existing profiles of patients illustrating that a higher proportion of women attend general practice than men (Welsh Office, 1998a). Women commonly take greater responsibility for health care needs of their family than men, which may account for the high proportion of women respondents in the current study. A Chi square test showed there was no significant association between gender and practice. The gender distribution of this sample is therefore representative of those attending general practice.

4.2.2 Age distribution

It can be seen from Table 4.3 that the sample is comprised of a slightly younger age group than the normal population in Wales.

Table 4.3: Comparison of sample with age distribution in Wales

Age (yrs)*	% in sample	% in population (ONS 2000a)
18 - 24	10	11
25 - 34	21	17
35 - 44	21	18
45 - 54	18	17
55 - 64	15	14
65 - 74	10	12
75+	5	11
Total	100	100

**Age groupings are based ONS 2000a*

A Chi square test of goodness of fit revealed no significant difference between the observed values from this study and the expected values in the population. The sample was therefore representative of the age groups in Wales. Table 4.4 shows that the distribution of age was similar for most of the age groups in each practice. A Chi square test showed no significant association between age and practice. The mean age is just over 45 years in each practice. The standard deviation is 16 years for each practice, which further illustrates the similarities in age distribution in each practice.

Table 4.4: Age distribution by practice

Age (yrs)	Practice 1 % (n)	Practice 2 % (n)
18 - 24	9 (49)	11 (30)
25 - 34	22 (119)	19 (51)
35 - 44	22 (120)	21 (56)
45 - 54	18 (102)	18 (48)
55 - 64	14 (80)	15 (41)
65 - 74	9 (52)	12 (33)
75+	6 (31)	4 (9)
Total*	100 (553)	100 (268)
Mean age	45.53	45.26
SD	16.38	16.41

**30 missing values for age*

4.2.3 Age distribution by gender

Women were mainly from the younger age bands with more than half aged 44 or less, compared to only 39% of men in this age group (Table 4.5). A Chi square test showed a significant association between age and gender at the 0.01 level (χ^2 = 28.84, df=6, p=0.00).

Table 4.5: Age distribution by gender

Age (yrs)	Men % (n)	Women % (n)
18 - 24	7 (19)	11 (60)
25 - 34	14 (38)	24 (132)
35 - 44	18 (48)	23 (128)
45 - 54	23 (61)	16 (89)
55 - 64	16 (43)	14 (78)
65 - 74	15 (39)	8 (46)
75+	7 (19)	4 (21)
Total*	100 (267)	100 (554)

**30 missing values*

These differences were explained by the observation that women accompanying children for appointments were likely to fall within the age range of 18-44. One possible reason for the higher proportion of older men is that younger men tend to visit their GP less frequently than women.

Figures from The National Survey of NHS Patients in General Practice (NHS Executive, 1999) show that older men were more likely to visit their GP, whereas women were more likely to be from younger age groups. A Chi square test of goodness of fit showed no significant differences between the distribution of gender by age against national figures (Table 4.6). These findings demonstrate that the current study sample was representative of the distribution of age according to gender in Wales.

Table 4.6: Comparison of age distribution by gender with national figures (ONS, 2000a)

Age (yrs)	Men (%)		Women (%)	
	Current study	*ONS 2000a*	*Current study*	*ONS 2000a*
18 - 24	7	11	11	10
25 - 34	14	18	24	16
35 - 44	18	19	23	18
45 - 54	23	18	16	17
55 - 64	16	15	14	14
65 - 74	15	11	8	12
75+	7	8	4	13
Total	100	100	100	100

4.2.4 Employment status

The Welsh Index of Multiple Deprivation was used to select two practices with different deprivation levels. Although this is a useful way to categorise the practices, additional measures were required to assess the socio-economic status of individual patients. The variables of employment and education were therefore included to determine socio-economic status. Any differences in employment and education status between the two practices would serve to reinforce the differences in the deprivation status of the practice populations.

Table 4.7 shows that the majority of patients were employed (54%, n=441) and a quarter were retired. The 'other' category included housewives/husbands and those patients who were self-employed or on long-term sickness.

Table 4.7: Employment status by practice

Status	Practice 1 % (n)	Practice 2 % (n)	Total sample % (n)
Employed	61 (336)	40 (105)	54 (441)
Unemployed	4 (23)	23 (60)	10 (83)
Retired	24 (132)	27 (73)	25 (205)
Student	3 (20)	2 (6)	3 (26)
Other	8 (43)	8 (21)	8 (64)
Total*	100 (554)	100 (265)	100 (819)

**32 missing values for employment status*

A very different picture was presented when the sample was broken down by practice. Although the majority of patients were employed, the proportion was much greater in Practice 1 (61%) than in Practice 2 (40%). The association between practice and employment was highly significant (χ^2 = 77.21, df=4, p= 0.00). This association was however expected due to the different levels of deprivation levels in each practice.

Patients were also asked to record their current or previous occupation. The occupations were categorised using the new Standard Occupational Classification (SOC) 2000 which replaced SOC 90. The SOC (ONS, 2000b; ONS, 2000c) comprises 9 occupational groups. Table 4.8 shows that there was a significant association between practice and occupation classification (χ^2 = 183.66, df=8, p=0.00).

Table 4.8: Occupation classification by practice; a comparison with national figures (ONS, 2001b)

Classification group	Practice 1 % (n)	Practice 2 % (n)	ONS 2001b (%)
1 Managers and senior	12 (47)	5 (7)	14
2 Professional	24 (94)	6 (8)	12
3 Associate professional/technical	21 (82)	6 (9)	13
4 Administrative and secretarial	24 (95)	8 (11)	13
5 Skilled trades	4 (15)	5 (7)	12
6 Personal service occupations	5 (21)	23 (33)	7
7 Sales and customer service	5 (19)	6 (9)	8
8 Process plant/machine operatives	1 (5)	14 (20)	9
9 Elementary	3 (11)	26 (37)	12
Total	100 (389)	100 (141)	100

In Practice 1 most (57%) of the patients were in categories 1-3, whereas in Practice 2 the majority (69%) were in categories 6-9. Figures from the Labour Force survey (ONS, 2001b) revealed that 39% of the population were categorised in group 1-3. This analysis confirms that patients from Practice 1 had a higher socio-economic status than those from Practice 2 and the Labour Force Survey.

4.2.5 Education

Patients recorded their highest level of qualification which ranged from no qualification to a Higher Degree. Table 4.9 shows that just under half (44%) of the patients from Practice 2 had no qualifications. This represents a much higher proportion than in Practice 1 where only 15% had no qualifications. A similar proportion of patients recorded GCSEs as the highest level of qualification in each practice. There were marked differences at degree level with 17% of patients from Practice 1 having a first degree compared to only 2% in Practice 2. The association between qualification levels and practice was highly significant ($\chi^2 = 136.32$, df=6, p=0.00).

Table 4.9: Highest level of qualification by practice

Highest level of qualification	Practice 1 % (n)	Practice 2 % (n)
No qualifications	15 (81)	44 (114)
GCSE	27 (151)	27 (71)
GNVQ/NVQ	7 (38)	13 (34)
A-Level	13 (70)	4 (11)
First Degree	17 (95)	2 (4)
Higher Degree	12 (66)	2 (6)
Other Qualification	9 (47)	8 (22)
Total*	100 (548)	100 (262)

**41 missing values for highest qualification*

Occupation and education data for the individual patients confirm the deprivation status of each practice location.

4.2.6 Non-respondents

Table 4.10 shows that 222 (21%) patients chose not to complete the questionnaire. Just over half (51%, n=113) of non-responders did not provide a reason for declining to take part. The remaining non-respondents provided a variety of reasons to explain non-participation, none of which could be considered to provide a potential bias in the sample.

The most common reason provided for non-response was that the participants did not have their glasses, which they needed to complete the questionnaire. This issue was highlighted in the pilot study and so in order to overcome this difficulty a large print version of the questionnaire was designed. Although this was offered to patients who did not have their glasses, only two chose to complete the large print version. It could be suggested that 'no glasses' is often the excuse for poor literacy; however the researcher has no evidence to support this claim.

Table 4.10: Non-respondents

Reason for refusal	Practice 1	Practice 2	Total
No reason	59	54	113
No glasses	13	34	47
Not registered at practice	11	2	13
Unwell/injured hand	9	3	12
Called for appointment	5	3	8
Accompanying young child	3	2	5
Distributed but not returned	2	4	6
Felt not applicable	3	2	5
Not interested	1	2	3
Reading difficulties	1	1	2
Sight problems	1	1	2
Taking part in other research	2	0	2
Didn't want to sign anything	0	1	1
Other work to complete	1	0	1
Not good at filling out forms	0	1	1
Under 18	1	0	1
Total	112	110	222

The second practice had a higher proportion of non-respondents than the first (P1 = 84%; P2=72%, see page 95). One possible reason for this was that patients from the second practice may have felt that the questionnaire did not apply to them as internet access is low in this area. However, the patient information sheet clearly stated that the questionnaire sought views from both users and non-users of the internet which should have addressed such concerns. The second practice is in a very deprived area and so some patients may have declined to complete the questionnaire due to poor literacy skills. Although only two patients from the practice stated this as a reason for non-response, this may account for the higher refusal rate.

It is unlikely that bias from the researcher affected the response rate as patients in each practice were approached in the same way. Patients were assured that participation was voluntary so they did not feel pressurised into completing the questionnaire due to the presence of the researcher. Overall, the response rates were high, which reduced biases associated with a high number of refusals. During this survey stage the researcher decided not to approach 25 patients from each practice, as distribution was considered inappropriate. The decision not to approach patients was mainly because the person appeared to be too unwell to complete the questionnaire.

4.3 Use of health information sources

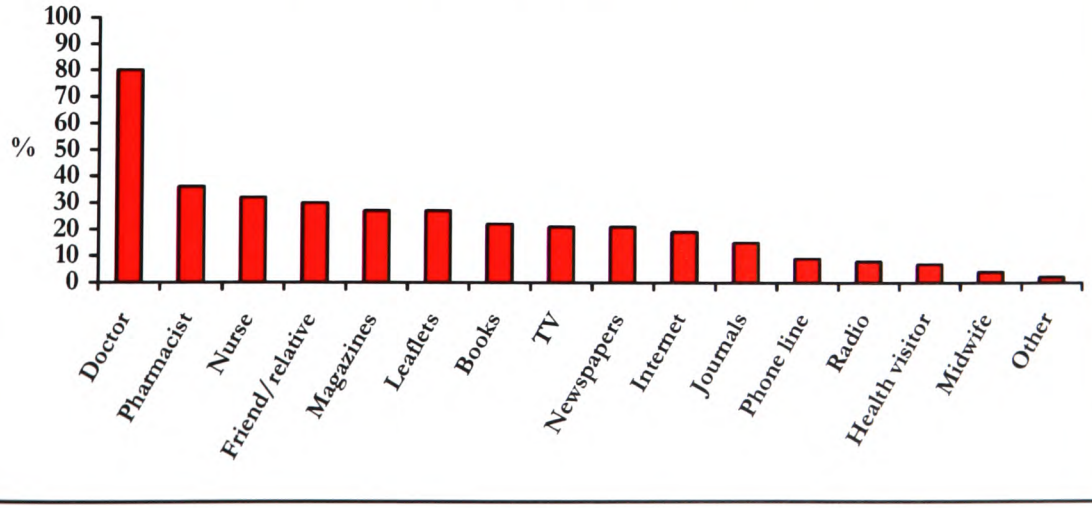
The first section of the questionnaire focused on the sources of health information that patients had used during the previous six months.

4.3.1 Sources of information about a specific illness used during the previous six months

The majority of patients used health professionals as the main source of health information. Figure 4.1 illustrates that the most frequently used source for information about a specific illness was the doctor (80%, n=677), followed by pharmacist (36%, n=303) and nurse (32%, n=275).

The survey was conducted in general practice and therefore a high number of participants would have recently used their doctor/nurse for information about a specific illness. Friends and relatives (30%, n=252) were the most frequently used informal source. Patients used many of the other sources of information more frequently than the internet, which was used by one-fifth of respondents (19%, n=162).

Figure 4.1: Sources of information about a specific illness used during the past 6 months

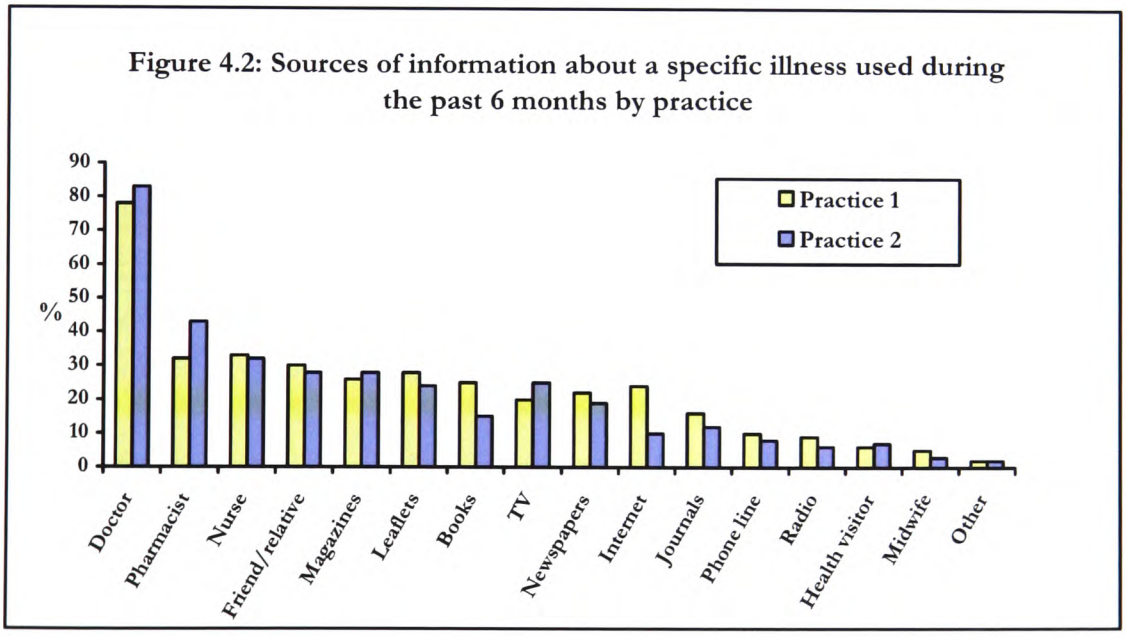


4.3.2 Information sources about a specific illness by practice

Overall, use of sources of information about a specific illness was similar in each practice. However, Figure 4.2 shows that there were a few distinct differences, with the most notable being use of the internet.

In Practice 1 just under a quarter (24%, n=135) of patients used the internet compared to only 10% (n=27) in Practice 2. A Chi square test illustrated a significant association between use of the internet about a specific illness and practice (χ^2 = 22.69, df=1, p=0.00). Books were also used more by patients from Practice 1 (25%, n=142) than Practice 2 (15%, n=43). This association was highly significant (χ^2 = 9.88, df=1, p=0.00). The pharmacist was the only source used more by patients from Practice 2 (43%, n=185) than Practice 1 (32%, n=118). This association was significant (χ^2 = 9.10, df=1, p=0.00).

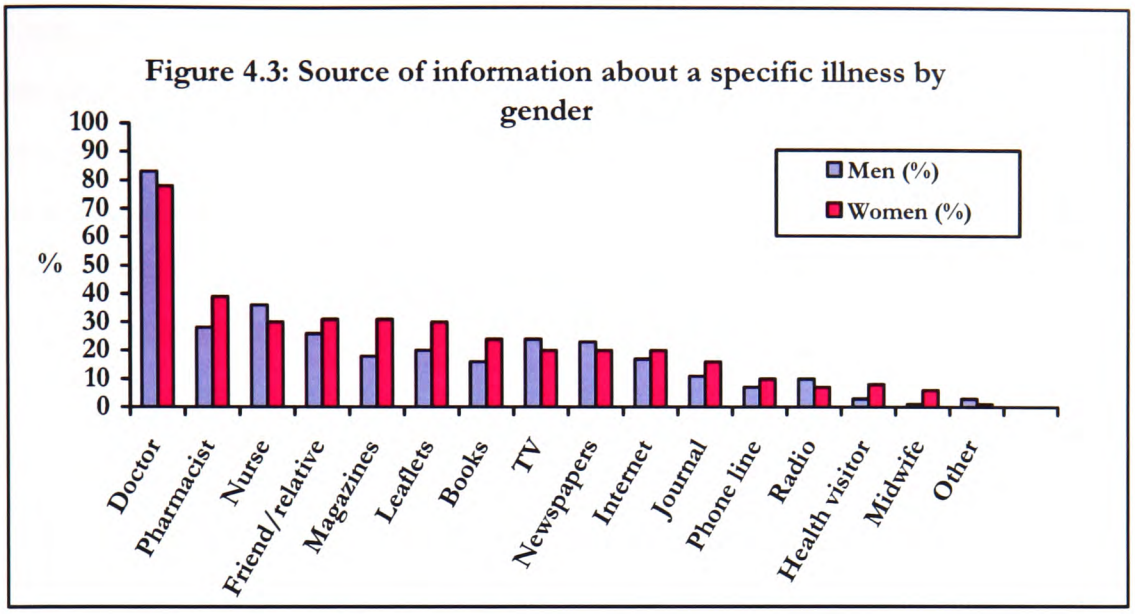
Figure 4.2: Sources of information about a specific illness used during the past 6 months by practice



4.3.3 Use of information sources about a specific illness by gender

In general, women used sources of information about a specific illness more than men. Figure 4.3 shows that the greatest distinction was made in the use of magazines which were used more by women (31%, n=174) than men (18%, n=48).

A Chi square test showed that this association was significant (χ^2 = 16.54, df=1, p=0.00).



There was also a significant association between gender and the use of the pharmacist, leaflets and books (See table 4.11).

Table 4.11: Gender differences in use of sources about a specific illness

Sources	Men % (n)	Women % (n)	Chi square	P value
Pharmacist	28 (76)	39 (218)	9.36	0.00
Leaflets	20 (55)	30 (165)	7.81	0.00
Books	16 (36)	24 (136)	7.59	0.00

With the exception of newspapers, women used all of the paper based sources significantly more than men. Men had accessed the TV, radio, newspaper, nurse and doctor more than women in the past 6 months for information about specific illnesses. None of these sources illustrated a significant association in their use according to gender. With the exception of health professionals, men accessed information from sources that were likely to be encountered spontaneously in everyday life rather than seeking particular sources for health, for example, a book or leaflet focusing on health.

4.3.4 Use of sources of information about a specific illness by age

Half of the information sources (8/16) showed insignificant differences according to age. Of the remaining sources, use of the radio, newspapers and nurses all increased with age. In contrast, telephone advice lines, the internet and friends/relatives were more popular with younger age groups. Unsurprisingly, midwives and health visitors were used more by the younger age categories who were of child bearing age. Younger people were more likely to use new technologies, yet older people relied more on the media and health professionals.

As the participants are not uniformly distributed over the different age groups (see table 4.12), Kruskall-Wallis (K-W) tests were used on the percentages from participants of different age groups for their use of different sources. These revealed significant differences ($\chi^2 = 30.52$, df=13, p=0.00) for the use of different sources but no significant differences ($\chi^2 = 3.11$, df=6, p=0.80) across different age groups. In this analysis, the two sources of Health Visitor and Midwife use for information about illnesses were combined with 'Other sources' due to their small values.

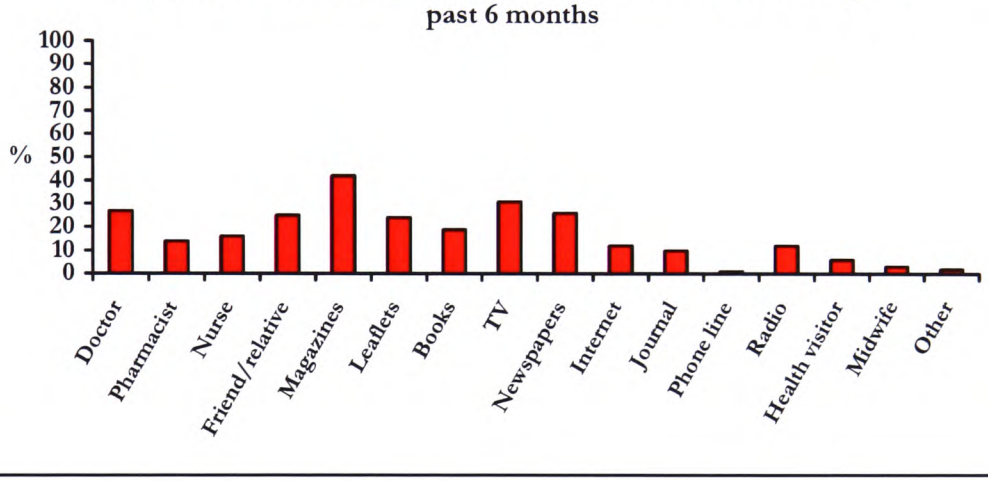
Table 4.12: Information sources about a specific illness by age

Information Source	18-24	25-34	35-44	45-54	55-64	65-74	75+	All ages
TV	6	5	7	5	6	7	5	6
Radio	2	1	2	2	3	3	2	2
Magazines	9	7	8	8	8	5	7	7
Newspapers	4	4	5	7	7	10	10	6
Journals	5	4	4	5	4	5	2	4
Books	6	7	7	6	4	6	4	6
Leaflets	7	8	7	8	8	7	5	7
Friends/ relatives	13	10	8	6	8	6	7	8
Phone advice line	2	4	3	3	1	1	1	3
Doctor	22	20	22	22	25	25	27	22
Nurse	8	6	7	9	12	13	14	9
Pharmacist	9	10	10	9	10	11	12	10
Internet	5	8	6	7	3	1	2	5
Other	4	8	4	1	1	1	2	4
Total	100	100	100	100	100	100	100	100

4.3.5 Sources of general health information used during the previous six months

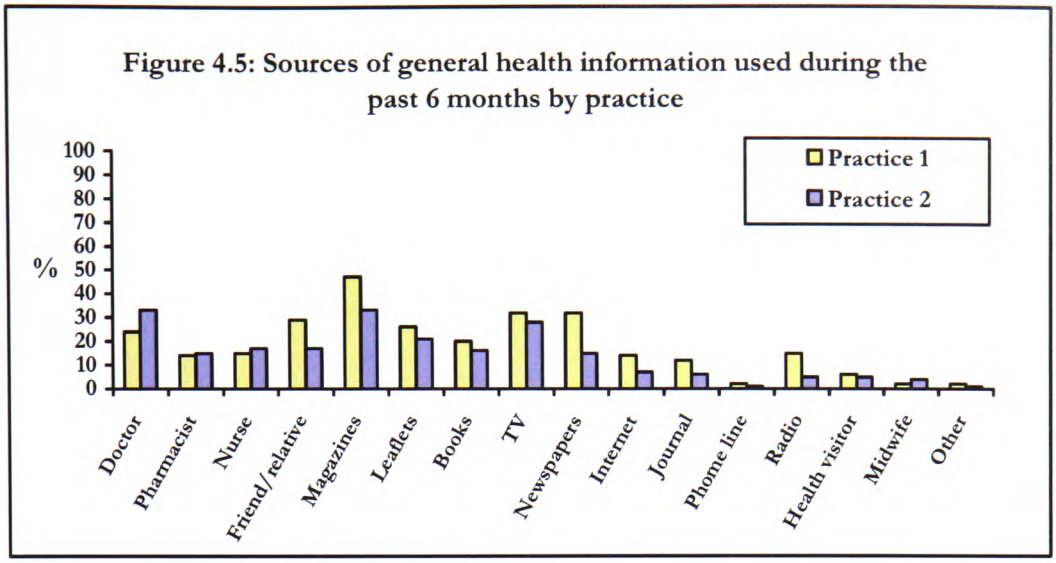
The sources patients used for general health information provided a different picture to those used for information about a specific illness. Figure 4.4 shows that the majority of patients used more informal sources such as magazines (42%, n=361) and the television (30%, n=260). In addition, a quarter of patients (27%, n= 230) used their doctor for general health information.

Figure 4.4: Sources of general health information used during the past 6 months



4.3.6 Use of sources of general health information by practice

Figure 4.5 reveals that patients from Practice 1 generally used most sources more than patients from Practice 2. Interestingly, as a source of information, patients from Practice 2 only used health professionals more than Practice 1. The greatest distinction was seen in use of the doctor which was used more by patients from Practice 2 (33%, n=90) than Practice 1 (24%, n=140). A Chi square test revealed a significant association between practice and use of the doctor (χ^2 = 6.54, df=1, p=0.01). This association suggests that patients from Practice 2 rely on health professionals significantly more than patients from Practice 1, who used a more diverse range of information sources.



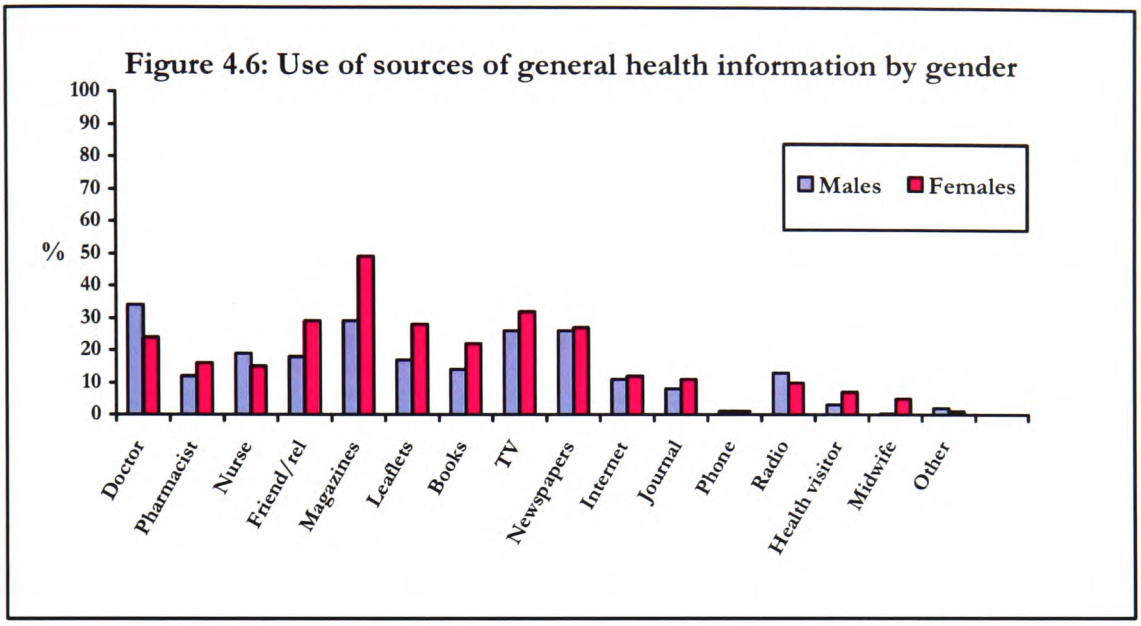
Patients from Practice 1 used two thirds of the total number of information sources more than patients from Practice 2. The greatest association was found in the use of newspapers by practice which were used twice as much in Practice 1 (32%, n=271) than Practice 2 (15%, n=90). A Chi square test showed that this association was significant (χ^2 = 25.97, df=1, p=0.00). Radio, friends/relatives, magazines, the internet and journals were also used significantly more by patients from Practice 1 than Practice 2 (Table 4.13).

Table 4.13: Sources of general health information by practice

Sources	Practice 1 % (n)	Practice 2 % (n)	Chi square	P value
Radio	15 (86)	5 (13)	19.04	0.00
Friends/relatives	29 (166)	17 (46)	14.84	0.00
Internet	14 (81)	7 (18)	10.38	0.00
Journals	12 (66)	6 (17)	5.99	0.01

4.3.7 Sources of general health information by gender

Figure 4.6 shows that women used most sources of general health information more frequently than men.



Women relied on paper based sources such as magazines, leaflets and books significantly more than men. They also used friends and relatives, midwives and health visitors significantly more than men (Table 4.14).

Table 4.14: Sources of general health information by gender

Sources	Men % (n)	Women % (n)	Chi square	P value
Magazines	29 (78)	49 (274)	30.18	0.00
Friends/relatives	18 (48)	29 (160)	11.39	0.00
Leaflets	17 (46)	28 (154)	10.99	0.00
Books	14 (121)	22 (38)	6.73	0.01
Midwife	0.4 (1)	5 (25)	10.08	0.00
Health visitor	3 (7)	7 (38)	6.27	0.01
Doctor	34 (92)	24 (135)	9.01	0.00

Men relied more on health professionals and used the doctor and nurse more than women. The association between gender and use of the doctor was highly significant (Table 4.14). Men also used the radio more than women; this association was not statistically significant.

4.3.8 Use of sources for general health information by age

Use of information sources about general health issues decreased with age. The only exceptions were using the doctor and nurse which increased with age. About 20% of patients aged 55+ used the nurse compared to around 10% of those aged 24-34 years.

The most notable finding was in the use of magazines which were used by two thirds of those aged 18-24 compared to only 20% of people aged 55+. Use of the internet also revealed differences according to age with 20% of 18-24 year olds using the internet compared to only 3% of those aged 75+. These results are consistent with earlier findings (page 107) as friends and relatives were used significantly more by younger people. Younger participa4nts clearly rely on a wider range of sources of general information than older people who rely on health professionals.

As indicated in section 4.3.4, Kruskall-Wallis (K-W) tests were used on the percentages of participants from different age groups for their use of different sources for general information. These revealed significant differences ($\chi^2 = 53.32$, df=12, p=0.00) for the use of different sources but no significant differences ($\chi^2 = 6.73$, df=6, p=0.34) across different age groups. In this analysis, the three sources of Telephone advice line, Health Visitor, Midwife use for general information were combined with 'Other sources' due to their small values (see table 4.15).

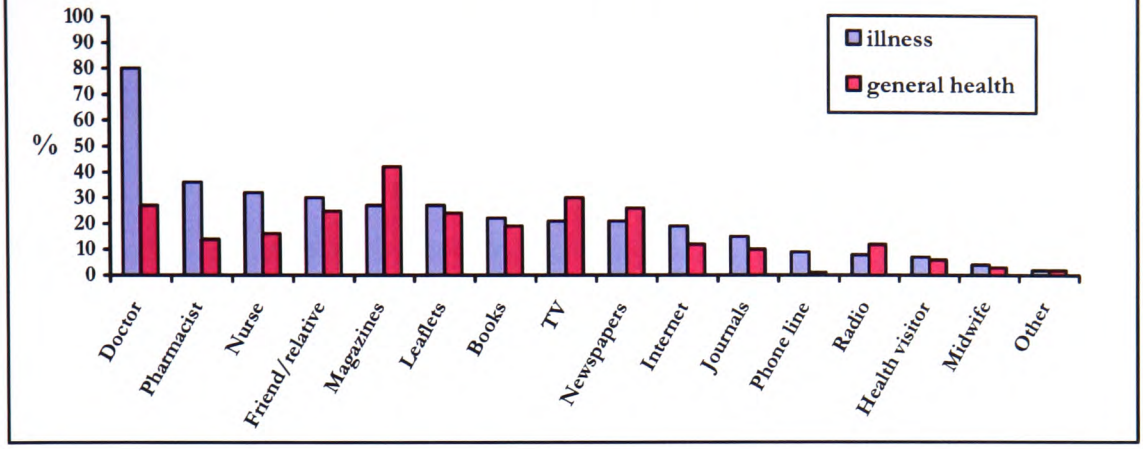
Table 4.15: General health information by age

Information Source	18-24	25-34	35-44	45-54	55-64	65-74	75+	All ages
TV	12	12	12	12	9	11	4	11
Radio	5	2	3	6	7	4	4	4
Magazines	20	15	16	15	15	14	12	16
Newspapers	7	6	9	13	13	13	12	10
Journals	3	4	3	4	3	2	9	4
Books	7	7	10	7	5	5	3	7
Leaflets	10	8	9	9	10	9	7	9
Friends/ relatives	12	13	9	7	6	6	6	9
Doctor	5	9	9	11	13	16	18	10
Nurse	3	4	6	5	9	11	13	6
Pharmacist	5	6	4	5	5	8	6	5
Internet	6	6	5	5	3	1	1	4
Other	5	8	5	2	1	0	3	4
Total	100	100	100	100	100	100	100	100

4.3.9 Sources of information about a specific illness and for general health

The majority of sources were used more for information about a specific illness than for general health. Overall, the doctor was the most widely used source of any type of health information. Patients used different sources of information about a specific illness than for general health information. Figure 4.7 shows that patients used health professionals significantly more (doctor, pharmacist and nurse) for information about a specific illness, yet used informal sources such as magazines significantly more for general health information. These findings are not surprising, as patients relied on health professionals for information about illnesses, yet may be content with informal sources for general health issues.

Figure 4.7: Sources used for information about a specific illness and general health issues



A Chi square test for goodness of fit showed a significant difference between the use of information sources about a specific illness and general health information (χ^2 = 380.15, df=15, p=0.00). The number of patients who used their doctor for information about a specific illness (n=677) was nearly three times greater than use for general health information (n=230). Magazines, newspapers, television and the radio were the only sources, with higher frequency counts for general health than for a specific illness. Magazines were used significantly more for general health issues (n=361) than for a specific illness (n=230; χ^2 = 86.16, df=1, p=0.00). Interestingly, all of these general health information sources are media based.

When all sixteen information sources were considered, patients used only a few of the sources at any one time. About half of the patients used a maximum of three sources of information about a specific illness (53%) and for general health information (58%). Table 4.16 shows similar mean values for the number of sources used for either purpose.

Table 4.16: Mean number of information sources used per person

Purpose of using sources	Practice 1	Practice 2	Total
Information about a specific illness	3.7	3.4	3.8
General health information	2.9	2.2	3.6

4.3.10 Sources of information used most often

Patients were asked to indicate which information source (from the list of 16) they used most often. The majority of patients used their doctor most frequently for information about a specific illness (61%, n=466). Books (6.7%, n=51) and the internet (6.5%, n=50) were the next most frequently used sources. This shows a different pattern to use during the past six months (See Figure 4.1, p 104), which showed greater reliance on health professionals. Again, this could be explained as respondents were attending general practice and so may have had a recent illness and therefore recently relied on health professionals for information.

The doctor was also the most frequently used source for information about general health issues (25%, n=173). This was closely followed by magazines (20%, n=137). These findings reinforce the pattern shown during the past six months (See Figure 4.3, p 106).

4.3.11 Sources of information patients prefer to use

A majority of patients (68%, n=503) preferred to use their doctor as an information source rather than other information sources. This finding was not surprising considering the frequency of use of the doctor as an information source in the past six months (80%, n=677). More surprisingly, the second most preferred source was the internet (6%). Although this was only represented by a small number (n=47) of patients, it was favoured over the other sources. Internet users may find this a more accessible resource for health information than making an appointment with their

GP/nurse. A similar picture was presented in each practice with patients choosing their doctor as a preferred source of information. However, slightly more patients from Practice 2 (75%, n=169) selected their doctor than in Practice 1 (65%, n=334). None of the patients from Practice 1 recorded the midwife as their preferred information source and none of the patients from Practice 2 recorded newspapers as their preferred source. Preferences for using information sources were evenly distributed according to gender. The only difference was displayed by those stating their doctor as a preferred source of information. A slightly greater proportion of men preferred their doctor (75%, n=316) as a source of information than women (65%, n=182).

4.4 Use of the internet for health

The second section of the questionnaire focussed on use of the internet for information about health issues. Non-users were asked to respond to a question about reasons for non-use.

4.4.1 Internet access by practice

Half (51%, n=426) of all patients had access to the internet with a marked difference between the two practices. Practice 1 had a much higher proportion of patients with internet access (62%, n=350) than Practice 2 (28%, n=76). A Chi square test showed a significant association between internet access and practice (χ^2 = 88.45, df=1, p=0.00). Practice 1 is situated in an affluent area which may partly explain the higher proportion of patients with access to the internet.

Practice 1 had a slightly higher rate of internet access than the national figures (56%) from the Omnibus Survey (2000b), whereas Practice 2 had a much lower rate of access. The national figures are based on a cross-section of areas in the UK. Differences between national figures and each practice were expected due to the different deprivation levels. An important point to consider when comparing figures from the current study with other surveys is the way internet access is defined. Internet access is sometimes described as those who currently have some

form of access (consistent with the current study) or may be those who have ever accessed the internet (ONS, 2002a).

4.4.2 Internet access by gender

Access to the internet was evenly distributed according to gender. Half of women (52%, n=291) and men (49%, n=132) had access to the internet. These findings present a slightly different scenario in comparison to national figures (Table 4.17). An e-MORI Survey (e-MORI, 2002) revealed that a higher proportion of men (57%) had some form of internet access than women (47%). A Chi square test for goodness of fit revealed that internet access in the current study was not significantly different to the national figures.

Table 4.17: Comparison of Internet access by gender with e-MORI figures

Gender	Current study % (n)	e-MORI (2002) % (n)
Women	52 (291)	47 (765)
Men	49 (132)	57 (928)

3 missing values for gender

4.4.3 Internet access by age

Younger patients represented the greatest proportion of all internet users. Those aged 25-44 accounted for half of internet users, compared to only 5% who were aged 65+ (Table 4.18). These findings can be partly attributed to the distribution of age in the current study, for example, fewer patients from the older age bands and more patients from the younger age bands. This can be illustrated by providing a breakdown of the proportion with internet access within each age group.

Table 4.18: Internet access by age

Age (yrs)	N	% Overall	% within category
18 - 24	50	12	63
25 - 34	106	25	62
35 - 44	107	25	61
45 - 54	94	22	63
55 - 64	44	11	36
65 - 74	16	4	19
75+	4	1	10
Total*	421	100	-

**5 missing values for age*

Table 4.18 also shows the proportion of internet users within each age group. Nearly two thirds of respondents from the age bands 18-54 had access to the internet. In contrast, only a third of patients aged 55-64 and 10% of patients aged 75 had internet access. The association between internet access and age category was significant ($\chi^2 = 101.40$, df=6, p=0.00).

Results from this study on internet access according to age were comparable to those reported in an e-MORI Poll. Table 4.19 shows internet users from the youngest age group appear to be under-represented in the current study. This was due to the differences in age banding (current study aged 18+, e-MORI aged 15+). A Chi square test for goodness of fit showed that these differences were not statistically significant.

Table 4.19: Internet access by age; comparison with e-MORI figures (2002)

Age (yrs)	Current study (%)	e-MORI Poll (%)
15-24	12 [1]	20
25-34	25	25
35-44	25	24
45-54	22	18
55-64	11	9
65+	5	3
Total	100	100

[1] This age banding is 18-24 years.

4.4.4 Internet access by employment

Internet access was unevenly distributed according to employment status. The majority of people who were employed at the time of the survey (67%, n= 294) had access to the internet compared to only 29% (n=24) of those unemployed. A Chi square test showed a significant association between employment status and internet access (χ^2 = 133.01, df=4, p=0.00).

Table 4.20 also shows differences in internet access and type of occupation. A high proportion (86%, n=87) of patients classified with a professional occupation had internet access, whereas only 27% (n=5) in skilled trades and elementary occupations had access to the internet. Over two thirds (n=15) of those working in sales and customer services had internet access. These results show that there is no trend in internet access according to this classification. The association between internet access and occupation was highly significant (χ^2 = 91.49, df=6, p=0.00).

Table 4.20: Internet access by occupation

Occupation classification (ONS, 2000b)	% (n)
1 Managers & senior officials	66 (36)
2 Professional occupations	86 (87)
3 Associate professional/technical occupations	71 (64)
4 Administrative & secretarial occupations	57 (59)
5 Skilled trades occupations	27 (5)
6 Personal service occupations	57 (30)
7 Sales and customer service occupations	68 (15)
8 Process plant and machine operatives	60 (5)
9 Elementary occupations	27 (11)

4.4.5 Education level and internet access

It can be seen from Table 4.21 that access to the internet increased with higher qualification levels. A Pearson's Correlation showed a small, but significant correlation between internet access and the level of qualification (r = 0.44, p=

<0.01)[2]. This correlation does not indicate a causal relationship between age and internet use, but suggests that those with a higher level of education have a greater exposure to the internet.

Table 4.21: Internet access by level of education

Highest qualification	% (n) with internet access	
	Practice 1	Practice 2
No qualifications	31 (25)	12 (14)
GCSE	57 (86)	31 (22)
GNVQ/NVQ	58 (22)	44 (15)
A-Level	64 (45)	64 (7)
First Degree	85 (81)	100 (4)
Higher degree	83 (55)	83 (5)
Other qualification	61 (28)	32 (7)
Total*	342	74

**10 missing values for level of education*

4.4.6 Internet access and professional qualification

Table 4.22 shows that about half of respondents (45%) with no professional qualifications had access to the internet. In contrast, the majority of teachers, doctors, dentists and other health professionals had much higher levels of internet access. Just over half (56%) of nurses/midwives or health visitors had access to the internet which was a lower proportion than any of the other professional groups. Over two thirds of people with an 'other' professional qualification had access to the internet. In general, respondents were more likely to have access to the internet if they had a professional qualification.

[2] Other qualification was not included in this analysis.

Table 4.22: Internet access by profession

Professional qualification	% (n)
Dentist	100 (3)
Other health care professional	91 (10)
Teacher	82 (45)
Medical doctor	75 (3)
Other professional qualification	67 (63)
Nurse/midwife/health visitor	56 (20)
No professional qualifications	45 (274)

4.4.7 Internet use by place

Patients were asked to state where they used the internet. Home or work was the most popular place to use the internet (Table 4.23). Few (5%, n=20) used the internet in public or other places. A similar pattern was reflected in figures from the UK Expenditure Survey (ONS, 2002a).

Table 4.23: Place of internet use; comparison with UK Expenditure Survey (2002a)

Place of access	Current study %	UK Expenditure & Food Survey %
Home	85	79
Work	42	35
Café	2	9
Library	2	8
Other	3	3

Table 4.24 demonstrates a majority of patients from each practice use the internet at home. Patients from Practice 2 predominantly used the internet from home (88%) with less than a quarter using it at work.

Table 4.24: Place where patients use the internet by practice

Place of access	Practice 1 % (n)	Practice 2 % (n)
Home	85 (294)	88 (65)
Work	47 (162)	22 (16)
Café	3 (9)	0
Library	1 (4)	5 (4)
Other	2 (8)	4 (3)

Nearly double the proportion of patients in Practice 1 (47%, n=162) used the internet from work in comparison to Practice 2 (22%, n=16). The association between using the internet at work and practice was highly significant ($\chi^2 = 15.70$, df =1, p=0.00). This association could be due to the type of employment patients were engaged in. Internet use was greater in groups 1-4 (professional, management and administrative) which were mainly represented by Practice 1. In contrast, employment categories 5-9 who are less likely to involve use of the internet were predominantly from Practice 2.

Men and women used the internet in similar places, with most using it at home. There was similar use according to age, although use of the internet at work decreased with age. This was expected as a greater proportion of older patients were retired.

A multiple regression model was constructed to further characterise internet access in terms of highest qualification, occupation and age which were found to be significant at least at the 0.05 level. An overall model was built to express the level of access to the internet by the entire sample and the same procedure was repeated for each practice. The latter helped to learn more about structural differences between the two practice populations in the strength of variables explaining internet access. For example, it was found that employment and highest qualification were insignificant within Practice 2 population but significant for Practice 1 (Appendix 17). Practice, occupation and age were negative contributors to internet access and highest qualification was a positive contributor. These are logically in line with the direction of the coding system.

The analyses by practice indicate more uniformity within the deprived than the affluent area (Appendix 17). It would then appear logical to attempt an analysis of the data at individual patient levels. However, investigating deprivation at individual levels requires postcodes for each patient so that their individual deprivation index could be calculated using the WIMD. Although individual postcode data were not available to perform this task, it has been shown that the two practices differ significantly in their deprivation levels and this effect has filtered down to other variables such as information use.

4.4.8 Length of internet use

Patients from Practice 1 had been using the internet for longer than those from Practice 2. Table 4.25 indicates that 11% of patients from Practice 1 had used the internet for 5 years or more, whereas in Practice 2 only 1% had used it for this length of time.

Table 4.25: Length of internet use by practice

Length of internet use	Practice 1 % (n)	Practice 2 % (n)
6 months or less	13 (46)	18 (13)
1 year	22 (77)	34 (25)
2 years	33 (113)	28 (21)
3 years	21 (71)	19 (14)
5 years or more	11 (38)	1 (1)
Total*	100 (345)	100 (74)

**7 missing values for length of use*

The association between length of internet use and practice may result from the cost of access to the internet. Patients from Practice 2 mainly access the internet from home, which has only recently become accessible to the wider population due to lower costs. Patients from Practice 1 were more likely to manage the higher home internet costs and therefore may have had access for a longer period of time than patients from Practice 2.

A comparison of gender and length of time of internet use showed that men had used the internet for longer than women. Over one third (38%) of men had used the internet for 3 years or more compared to only 25% of women (Table 4.26).

Table 4.26: Length of internet use by gender

Time used internet	Men % (n)	Women % (n)
6 months or less	10 (13)	16 (46)
1 year	19 (24)	27 (76)
2 years	33 (43)	32 (91)
3 years	25 (33)	18 (52)
5 years or more	13 (17)	7 (21)
Total	100 (130)	100 (286)

**10 missing values*

A Chi square test showed a significant association between the length of internet use and gender (χ^2 = 10.31, df=4, p=0.04). There was however, little difference in the length of internet use according to age.

4.4.9 Use of the internet for health information

Just over half (52%, n= 220) of internet users accessed health information online (Table 4.27). A similar scenario was presented according to each practice.

Table 4.27: Use of the internet for health information

Practice	% (n)
Practice 1	51 (179)
Practice 2	54 (41)
Total sample	52 (220)

There were similar patterns according to gender with about half of men (50%, n=65) and women (54%, n=155) using health internet information. Half of most age groups accessed health information on the internet; however only 25% of those aged 65 or above accessed the health internet. Overall, only 19% (162) of the sample had used the internet about specific illnesses in the previous six months (p102). However, this represents the majority (74%) of health internet users, indicating that most had made recent use of the internet.

4.4.10 Use of internet health information and length of internet use

Use of health information increased steadily with the length of time respondents had used the internet (Table 4.28). A Pearson's Correlation showed a weak correlation between accessing health information and length of internet use (r = 0.207). Although, statistically significant (<0.01), it was concluded that there was a weak association between use of health information and length of internet use. Patients may feel more comfortable accessing the internet for health once they gain experience of using the internet. Alternatively, they may be more likely to have come across health information due to increased time spent on the internet.

Table 4.28: Accessing health information and length of internet use

Length of internet use	Use of health information % (n)
6 months or less	33 (19)
1 year	49 (50)
2 years	54 (71)
3 years	59 (50)
5 years or more	76 (29)

4.4.11 Discussion of internet health information during consultations

Just under a quarter (24%, n=55) of health internet users had discussed internet information during a consultation with a health professional. Patients from Practice 1 (26%, n=48) had discussed information in consultations more than patients from Practice 2 (17%, n=7). A Chi square test showed that the association between practice and use of information in consultations was not significant. There were similarities according to gender with about a quarter of men and women discussing internet information during consultations. There was an even distribution according to age with about a third of most age bands discussing internet information during consultations.

4.4.12 Views about using health internet information during consultations

Most patients were positive about discussing internet information during a subsequent consultation (Table 4.29). Three quarters of respondents felt more prepared and able to participate in decision making when they used health information from the internet in consultations. However, some patients were more sceptical about internet information with over half trusting their health professional more than the internet. About half felt that the consultation was more effective, yet only a third (36%) felt that the health professionals listened to them more. One-fifth had introduced information that was new to the health care professional or felt that the consultation time increased.

Table 4.29: Agreement with statements about use of internet information during consultations

Statement	% (n)
I feel more prepared	75 (41)
I feel that I can participate more in decisions about treatment and care	72 (38)
I trust my health care professional more than the internet	55 (29)
The consultation is more effective	43 (23)
My health care professional listens more to what I have to say	36 (19)
I have introduced information that is new to the health care professional	21 (11)
The consultation time increases	21 (11)

A comparison of the views of men and women revealed very similar perceptions. In general, there were also similar views according to practice.

4.4.13 Non-users of the internet for health

Most non-health internet users preferred to access health professionals (89%) or use other information sources (73%) than the internet (Table 4.30). Given the concerns about the quality of internet information, surprisingly, only 21% did not access health information because they did not trust the internet.

Table 4.30: Non-use of the internet for health information

Statements	Practice 1 (%)	Practice 2 (%)	Total (%)
If I want health information I would ask a health care professional	87	90	89
I prefer to use other sources of health information	76	54	73
I have no reason to use the internet	36	38	36
I do not know how to use the internet	22	33	24
I do not trust health information on the internet	18	33	21
I have tried using the internet and have not found the information useful	16	22	17
I find the information too difficult to understand	2	25	6

Internet skills were not the major deterrent of health internet use. A quarter (24%) did not know how to use the internet for health sources, yet only 6% had difficulties understanding internet information.

The reasons for non-use of the health internet provided a different pattern according to practice. Patients preferred to access health professionals rather than the internet; however patients from Practice 1 preferred to use other information sources more than those from Practice 2. A Chi square test showed no significant association between non-use of the internet for health and practice. Reasons for non-use of the health internet were comparable for gender. There were minimal differences according to age.

4.5 Health value

This section provides information about the value that respondents placed on their health. Patients were asked to complete a health value scale (Lau *et al.*, 1986) to explore the relationship between health value and use of information sources. The health value scale comprises 4 statements about health. Each statement is rated from 1 to 7, resulting in a minimum possible score of 4 and a maximum score of 28 (Appendix 9). The higher the overall score, the greater value the person places on their health.

4.5.1 Health value score

The scores were banded into five categories of health value, from very low to very high health value. Table 4.31 shows that most patients placed a high value on their health. Nearly three quarters (71%) of patients had an overall score of 19 or above.

Table 4.31: Overall health value score

Health value score	% (n)
Very high (24 to 28)	38 (279)
High (19 to 23)	33 (237)
Moderate (14 to 18)	24 (173)
Low (9 to 13)	5 (36)
Very low (4 to 8)	1 (4)
Total*	100 (729)
Mean	21.86
SD	4.46

** 122 missing values*

Table 4.32 shows that these figures are comparable with other studies using the health value scale.

Table 4.32: Comparison of health value with other studies

Sample	N	Mean	SD
Current study	729	21.86	4.46
Ulcer clinic patients	74	22.49	5.19
University students	1026	20.34	4.41
University students' parents	940	22.95	4.18

Cited by Lau et al. (1986)

Overall, respondents had comparable health value scores according to practice, gender and age (Table 4.33-4.35).

Table 4.33: Health value by practice

Practice	N	Mean	SD
1	510	21.82	4.45
2	219	21.96	4.53

Table 4.34: Health value by gender

Gender	N	Mean	SD
Men	494	21.95	4.42
Women	235	21.67	4.57

Table 4.35: Summary; health value scores by age

Age	N	Mean	SD
18-24	76	20.14	4.02
25-34	164	21.18	4.36
35-44	165	21.44	4.51
45-54	127	23.00	4.25
55-64	102	23.00	4.58
65-74	66	22.68	4.10
75+	27	21.44	5.18
Total	727	21.85	4.47

A recent small-scale study of elderly adults' (n=42; mean age 72) investigated whether use of the internet led to changes in perceptions of health (Campbell *et al.*, 2005). The health value scale revealed a mean value of 18.02, which was lower than patients from the older age bands in the current study. The health value score did not reveal a significant impact between internet use and health value. Participants were recruited using a convenience sample of the general public which could explain the lower health value. Overall, patients in this study had higher health value scores. This sample was selected from people accessing primary health care services and so could explain the higher health value people place on their health.

4.5.2 Health value and use of the internet

A comparison of health value score and use of the internet for health revealed that health internet users had a slightly higher health value score (Table 4.36). A Chi square test showed that this association was not significant.

Table 4.36: Frequency count; use of the health internet by health value score

Used health internet	V. Low	Low	Moderate	High	V. High	Total
Yes	1	7	57	68	80	213
No	1	17	39	64	59	180

4.6 Summary of main findings

Representativeness of the sample

Overall, the sample was representative of general practice but less representative of the community due to the unequal gender distribution. Women accounted for a greater proportion of the population than men which was representative of general practice. Age was fairly evenly distributed, representing the normal age distribution in Wales. The distribution of age and gender was similar according to practice. There were practice differences in employment status, occupational class and education. These findings provided evidence to support the differing levels of deprivation in each practice population.

Patients' use of health information *(Study objective 1)*

Patients relied on health professionals more for health information than any other source. The doctor was by far the most popular source of information about a specific illness. In contrast, informal sources such as magazines were more widely used for general health information. Patients used a small number of information sources, rather than using a diverse range of sources. Health care professionals and paper based sources were the most commonly used sources during the previous six months. Overall, the doctor (68%) was the most preferred information source followed by the internet (6%). The internet and paper based sources were the most popular sources used during these consultations with health professionals. The majority of patients placed a high value on their health.

Socio-economic factors and the use of health information sources *(Study objective 2)*

Patients in the practice with the higher socio-economic status used a wider variety of information sources. Those in the practice with a lower socio-economic status relied more on health care professionals for information.

Women used more information sources than men. Women relied more on paper based sources such as magazines, while men used media sources and health professionals. Women were more likely to access sources about general health issues, yet men used sources more for information about a specific illness.

Younger patients used more information sources than older patients. Younger generations used new technologies, and older patients relied more on health professionals.

Health value scores were across the sampling categories similar according to socio-economic status, practice, gender and age.

The internet as an information source *(Study objective 3)*

Just over half of all patients had access to the internet. Access to the internet was not equally distributed by socioeconomic status, with nearly three times as many patients from affluent areas having access to the internet than those in more deprived areas. Internet access was equally distributed by gender with half of men and women having access to the internet. Internet access also varied according to age with far more younger people having internet access than older people. Participants with professional job/qualifications and higher education qualifications (predominantly from the more affluent area) were more likely to have access to the internet.

Most used the internet at home or at work. Over twice as many patients from affluent areas used the internet at work. They also had experience of using the internet for longer periods of time than patients from deprived areas.

From the sample overall, a fifth (19%) had used the internet for information about an illness during the past six months and 12% had used it for more general health information. About half of all internet users accessed health information. This distribution was consistent across socio-economic status, gender and age. Some patients (25%) had used the internet for discussions in consultations with health professionals. Such use was viewed fairly positively, with patients feeling more prepared and able to take part in decision making. Most of those who chose not to use the internet for health preferred to access other sources (primarily health professionals). Views about use and non-use of the internet for health were fairly similar across socioeconomic status, gender and age.

Objectives four and five will be addressed in chapters five (pp 132 - 170) and six (pp 171- 187).

CHAPTER FIVE

INTERVIEW RESULTS

5. 1 Introduction

This chapter presents the results from interviews with patients (n=50) and health professionals (n=10). Themes were generated from principal questions in the interview guide and newly emerging themes discovered during an inductive analysis. The central focus is on patients' use of internet information in primary care. The findings also explore use of other health information sources identified in the survey stage. The results are organised into four main themes which are presented as a narrative account and supported by illustrative quotations.

5.2 Sample profile

Patients willing to be interviewed were identified at the survey stage. Participants were then selected using a purposive sample according to age and internet use (pp 70-73). Non-response from volunteers did not allow for a perfect demographic match. A total of 50 patients were interviewed which included users and non-users of the internet (Table 5.1).

Table 5.1: Profile of patient interviews

Age	Internet users	Non-users	Total
18-54	22	10	32
55-64	5	5	10
65+	3	5	8
Total	30	20	50

Overall, the interviewees were representative of the survey sample and by practice. Two thirds (68%) of patients were from Practice 1 and 16 (32%) were from Practice 2. Gender distribution was also representative of the survey with 68% comprising women and 32% men. There were however gender differences between practices with over three quarters of women in the sample from Practice 1. Table 5.2 illustrates that Practice 2 had an even distribution according to

gender, whereas in Practice 1 there were over three times as many women in comparison to men.

Table 5.2: Practice by gender

Practice	Male % (n)	Female % (n)
1	50 (8)	79 (26)
2	50 (8)	24 (8)
Total	100 (16)	100 (34)

Age was also representative of the survey sample with two thirds of patients aged 18-54 and a fifth aged 55-64 and 65+ respectively.

A selection of staff from each practice agreed to be interviewed. It was not possible to conduct an interview with one of the GPs from Practice 2. This GP did agree to be interviewed, but despite numerous attempts to arrange the interview it was not possible for the researcher to arrange a convenient time. This GP was particularly reluctant to use technology which may have explained why the interview was not carried out. This non-response was disappointing for the researcher as the interview could have provided a valuable insight into the views of a health professional who was resistant to technology. During Phase 2 of the study, Practice 2 had a vacancy for a practice nurse, so it was only possible to interview one practice nurse. Table 5.3 provides details of the staff interviewed from each practice.

Table 5.3: Profile of staff interviews

Practice	GP	Nurse	Receptionist	Practice manager	Total
1	2	2	1	1	6
2	1	1	1	1	4
Total	3	3	2	2	10

5.3 Interview themes

It was clear from the interviews that patients sought information in different ways depending on their health information needs. Using the internet was a complex process which surpassed issues of access and technical ability. The interviews provided a detailed insight into how users made sense of internet information in the context of their own health. These issues were captured in four themes.

(i) Approaches to information seeking - the ways in which patients access sources of information about health issues.

(ii) Managing the internet - access and use of the internet, including searching strategies and interpreting health information.

(iii) Using health internet information - ways in which information from the internet are applied to health.

(iv) Patient-centred care - the role of health internet information in placing patients at the centre of primary care.

These themes represent the views of patients and practice staff. The use of health information according to socio-economic factors such as practice, gender and age are presented throughout, for each of the four themes. Appendix 18 provides a list of the final coding.

5.4 Approaches to information seeking

Patients described two main approaches when seeking information about health. Firstly, unplanned or passive access to health information and secondly, more active searches that were conducted to meet a specific health need.

5.4.1 Passive discovery

The majority of patients encountered health information passively, for example, when browsing a magazine or newspaper. This approach was an opportunistic way of accessing information that patients did not *'look for'* or *'seek out'*. A variety

of sources provided access to health information, yet initially patients found it difficult to pinpoint a primary information source. As the interviews progressed, patients realised the extent to which they encountered health information in their everyday lives. This type of information focussed on more general issues, categorised as lifestyle and well-being and was most commonly found in media sources such as the TV, radio, newspapers and magazines.

> *I always like to hear things about a healthy diet. I would say that I do try to bring up my family according to latest research. I wouldn't say I actively go out looking for these things but I am always aware of it. I don't know where it all comes from really. I don't really read glossy magazines and I do watch the news and read papers. (PT21, P1).*[1]

> *It would be what I happen to come across really. We take the Guardian and they have a health section in there and I listen to Woman's Hour, for example, and You and Yours, that sort of programme on television, the radio rather, and quite a lot of information comes from those, but I don't seek out much information (PT41, P1).*

There was little resistance to the reception of unsolicited information. Patients were content to engage with or ignore this information, depending on its perceived relevance. Patients demonstrated genuine interest in such health information and would take the time to absorb it even though they had not initiated a search for it. Accessing general health information was ad-hoc and so was more difficult for individuals to use in a meaningful way.

Over two thirds of interview patients accessed information passively in Practice 1, compared to less than half in Practice 2. Women from both practices were more likely to access information passively than men. These differences may be explained by the use of information sources illustrated in the survey. Patients from Practice 1 accessed more sources about general information, more frequently, than patients from Practice 2. Women also accessed far more information sources for general issues than men (p 110). The survey and interviews both demonstrated that men had less interest in their general health than women. There were also differences according to age. Two thirds of patients

aged 35-44 talked about passive discovery of information compared to only a third of patients aged 65-74. These differences support the findings from the survey which revealed that older patients accessed less information about their general health than younger patients (pp 111-12).

5.4.2 Active searching

In contrast to passive approaches, patients demonstrated more purposive forms of information seeking. This style of searching was based on a *'conscious decision'* to look for issues of *'relevance'* and *'personal interest',* which warranted a more structured approach. Other motivations resulted from symptoms of illness, or a specific condition.

> *Only if I had a particular problem. I don't just look up on heart stuff I have got sciatica at the moment, I looked stuff up on that. My husband has got a problem, I looked that up, anything really that affects us rather than looking in the abstract probably (PT17, P1).*

Nearly all patients from each practice actively searched for information about specific diseases. These were predominantly chronic conditions which patients were frustrated with as they were unresolved or had no effective treatment. Seeking information helped them gain further insights into their illness. There was a need to search *'for things I've been touched by'* and a sense that patients wanted to make it clear that their searches were justified. One patient rationalised their searching:

> *I would never go on and just look something up for the hell of it. It would only be if it affected me personally or if somebody at work said I've got this problem, or my Dad's ill with this or what have you, so that I have the knowledge to help and support them more than anything (PT49, P1).*

Many comments revealed a defensive attitude to information seeking which was used to legitimise their searches. For example, *'If I have a condition I will seek information'*. Many tried to emphasise genuine concerns and that they were not hypochondriacs who spent too much time on the internet or bothering their GP.

> *I don't see the point in looking for information if there's nothing wrong with you. No it's not something that I'd take up as a hobby or anything, no (PT25, P1).*

In comparison to other sources, the internet was considered a particularly useful source for detailed information about conditions.

Accessing material specific to particular aspects of diseases and how drugs work were cited as examples of the type of information which was of particular value.

> *If I needed information I would go straight to the internet, because I know also there are new drugs on there that come out for different diseases and conditions. Sometimes you can get information on there and then you can come to your doctor and say well, this has been passed, can I have a prescription for this to help me with that (PT 14, P1).*

This approach to information seeking can be seen as typically reactive, due to worsening health status. Patients therefore sought information when a problem arose, or to gain an insight into an existing health concern. Given that nearly all patients engaged in active searching there were no differences according to practice, gender or age.

Intermediary searching

Several patients accessed information on behalf of others to offer support or interest in other people's health concerns. Information was described as *'not directly for myself'* or *'I am never in need as I am not ill'*. Although most of these

searches were conducted in a parental role, people were attentive to the health needs of others, such as neighbours.

> *If there's anything else, for example one of my neighbours who has a kidney problem and I have looked it up in most of my books, but I also looked it up on the internet to get some information for her, because she wasn't on the internet, to see if there were leaflets and things like that, that I could give her about her condition. (PT2, P1).*

There was evidence that people relied on informal networks of support for exchanging information.

> *I belong to a French Group and they're all very health orientated, we swap notes and health advice. I'm always interested in others people's symptoms.... I would ask friends, what sort of symptoms they had, or did they know anybody that had it (PT23, P1).*

The extent to which people accessed informal information depended on the type of support networks that were available. The impact of such information networks can vary, for example, some information may be a source of reassurance, whereas others act as a trigger for seeking additional information. Practice staff also commented on the use of informal sources to exchange health experiences:

> *I don't know if there's anything else here, word-of-mouth, a lot of people discuss things...we get women who come in for their first smear and they say well we've all been talking about it, we are all due to come in, we're scared what does it mean, what are you looking for (Nurse 2, P1).*

Nearly all of these intermediary searches were conducted by women. Only one male described use of a medical book to look up something for his child. Findings from the survey data revealed that women accessed more health information and were more likely to seek information for others. Younger patients were also more likely to search for others than their older counterparts. Nearly two thirds of patients aged 25-44 accessed information for others

compared to only a quarter of patients aged 55-74. These findings can be explained by a greater reliance on friends and relatives for health information by women and younger patients (pp 110-11).

5.5 Managing the internet

In general, patients were positive about using the internet as it offered accessibility, depth and variety of health information. These issues were highlighted in discussions about access to the internet, internet searching, quantity of information, understanding information, trustworthiness of information and future ICT trends. The views of non-users of the internet were also included if they expressed opinions about managing health internet information.

5.5.1 Access

The ability to access a variety of information sources was an important consideration for patients and practice staff. Many factors impact on the availability of information, for example, the internet may not be freely available or some sectors of society may be unable to afford access to the internet. Staff and patients only referred to inequality of access concerning the internet; this was not discussed in relation to any other information source. Inequalities in patient access to the internet were of particular concern to staff in Practice 2, which is in a more deprived area. One GP proposed setting up a computer for patients to access information in the surgery waiting room. The GP had not discussed this idea with the other partners and so it was not planned for the immediate future.

The survey showed that half of all patients had access to the internet (p 115). The interview sample was chosen to explore the views of internet users and non-users. Although some patients were non-users at the time of the survey, a small proportion had acquired the internet for the first time since the survey. The interviews also revealed that although patients did not have personal access (home or work) they often had indirect access through others.

Yes I have used it, I can't actually do it myself, my daughter...in fact we looked something up the other day because her boyfriend was having a tooth extracted and he's got a heart murmur, she was a bit concerned about this, then I said to her why doesn't she look it up on the internet (PT13, P1).

A friend of mine was having problems with her hands and the doctor couldn't seem to get to the bottom of it, I actually told my daughter and then she looked it up on the internet and said it sounds like carpal tunnel syndrome. I gave my friend all the information and she said it is exactly as it's written down (PT25, P1).

Indirect access was more common in Practice 1 with a third of those categorised as non-users accessing the internet indirectly through others compared to only a fifth in Practice 2. Only one person accessed the internet elsewhere, at the library. Patients may be unaware that public access to the internet is available, and often free, at venues such as the library, though were not specifically asked about this.

The majority of those with any form of access used it for health information. Only 5 internet users had not used it for health, mainly as they were infrequent users of the internet, or due to lack of time. An advantage of using the internet was the ability to access up-to-date information, quickly, in the privacy of the person's own home. Searching for information about personal health issues was much easier in a private context. Some internet users felt that they would use the internet more for health information if they had more time and had access at home.

I think that way it's a good idea; you could access the information you want in the comfort and privacy of your own home and take the time you want to read or do things (PT34, P2).

I think with the internet, you can get exactly what you want immediately. You can get the information you want immediately, whereas with a book you have to search yourself.... (PT17, P1)

The internet was praised for the variety of information, much of which would be difficult to access from other sources. For example, information could be accessed from all over the world. Patients and practice staff also commended the increase in patient-oriented websites as they provided an opportunity to gain insights into patient perspectives and shared experiences:

> *Oh brilliant yeah because with the cytology they give me all people's experiences and case studies and it all came though on the internet, it was really good you know what people had been through (Nurse, P2).*

All practice staff were active users of the internet with the exception of a nurse from Practice 1. All had access at their practice, but time constraints prevented use during working hours. Nearly all staff had access in their own homes too, which was the most popular form of use. Health professionals rarely used the internet to seek information during consultations. However, such use was perceived positively as information could be accessed and discussed with the patient when the need arose. Such discussion was generally viewed as unrealistic in practice, due to time constraints in consultations. Internet searches were sometimes conducted post-consultation; however this was predominantly performed at home, outside working hours.

> *I was able to actually just access the internet there and then and type it (Forestier's Disease) into a search engine. I found a site that described it in such a way that made it very, very easy for the patient to understand. I also found out what it was as well (laugh) (GP1, P1).*

> *It's not fast enough; I mean basically that's the problem. I mean it takes me a second to click down a normal consultation screen to go into a search engine, but to actually access information is just too lengthy, you know the waits between downloading things, getting to the right things, it doesn't work in a ten minute consultation (GP2, P1).*

Non-users of the internet

Cost was a factor for a minority of patients without access but lack of time or interest had a greater impact on non-use. The most common reason for not accessing the internet was age. The internet was strongly perceived as a tool for young people to use. Patients from older generations felt it was *'too late'* for them to use the internet and that it was more suited to younger generations.

> *I can't see me buying a computer, no. I use the games you know golf games I have used it in that respect but not the internet.... Well I am getting too old now, 67 see. It is for youngsters (PT29, P2).*

Nearly all non-users aged 65+ did not foresee themselves accessing the internet in the future. However, these views did not apply to all patients from older generations. The oldest internet user was a 79 year old lady from Practice 2, who was a very active and frequent user of the internet. She described the ways in which she organised her searching:

> *I have got a huge book of a lot of addresses and I use that, and if I see anything on television with something that I would be interested in, I would take down the web address (PT 31, P2).*

Non-users discussed the potential value of using the internet. Even those without the skills or access to the internet had a general awareness that it could be a helpful source of information. Many non-users felt the internet had the capacity to give an in-depth insight into health. There were occasions when the internet could have fulfilled a need for further information. This perception was based on patients' interpretation of the internet, rather than exposure to this resource. There appeared to be an enigmatic quality to the internet that was viewed as a potentially powerful tool by those who did not have access.

Yes because I'm not really sure how to do it but I would imagine it is very good for getting information. You only need to put in so much information and you can get such a lot back from it. My sister uses it a lot she's got arthritis so she's done a lot of searching, you know for new drugs and things like that, it's been a great help to her (PT13, P1).

5.5.2 Searching strategies

Staff and patients described a variety of ways in which they searched the internet for health information. Search engines were a common way for staff and patients to gain information with the most popular being Google and Ask Jeeves. Patients generally managed to retrieve relevant information, yet they encountered a huge volume of information from general search engines (pp 148-49). The number of hits from search engines were described as *'overwhelming'*, with *'millions of different websites'*.

I just got on to a search engine and asked for particular sugar diabetics or diabetes. I found lots of different pages of different information and then they list specific things. Because I don't know much about it I wasn't able to pinpoint specific things, I just read through it all (PT30, P2).

Adopting this type of search produced a considerable amount of information. Consequently, there was an awareness that searches had to be fairly specific in order to obtain relevant information. Conducting a successful search was one way to reduce the time spent on the internet. Patients recalled times when they did not realise how long they had been searching as they had followed a series of links and accessed a multiplicity of information that was less relevant to their original search. Using a specific term or *'buzz word'* was an accepted part of the process. It was acknowledged through trial and error that relevant information was most successfully obtained by using a specific term.

Yes, sometimes you have trouble with the search engines, you have got to try to be as specific as possible, you can't put in just, I don't know....headache or something like that, you have got to be more specific than that, but if you can it's pretty good (PT33, P2).

Time taken to search was of greater concern for practice staff, especially when conducting searches during the working day. One nurse commented: *It's time, because it takes so long to search the thing sometimes. (Nurse 1, P1).* All health professionals from each practice used specific websites such as the BMJ, Doctor's Net and the Cochrane Database. Most staff were fairly organised and stored popular websites in their favourites. Where appropriate they referred patients to particular websites, but this was not done on a routine basis:

There will be a certain number of patients who are Diabetic or in the Diabetic Clinic. It's fine they've come already for a consultation to the surgery. You can tell them to go on the site, or go and have a look on the internet about the disease and what you can do to help yourself. Yes it has helped (GP2, P1).

Brief references were made to the interactive nature of the internet, which was more engaging than reading paper-based sources. Patients used specific websites more frequently than search engines as they were more user-friendly. Triggers to named websites were derived from sources such as leaflets, magazines and the television. There was an increased feeling of confidence about websites that were recommended by others. Both GPs from Practice 1 talked about referring patients to websites; however, patients did not mention these referrals.

Yes very definitely there are a few Mental Health websites that I've used as well, that I do give practically every patient that I actually, who I diagnose with Mental Health problems. I do get feed back with them (patients) that those can be useful (GP2, P1).

Of the remaining practice staff there was broad consensus about the benefits of referring patients to specific websites that were of known quality and relevance. These staff did not refer patients to websites as they were not confident in their

ability to use the internet, or they did not have extensive knowledge of websites that would be appropriate for patients. Lack of confidence was of particular concern for nurses, as one described:

> *Yes as I probably got more into the internet I probably would like to use it more. I think it is good, but as I don't use it a lot perhaps I don't tell patients to use it. If I got into it I'd say to them you can get this off the internet, you could go home and actually print it off the internet as well (Nurse 2, P2).*

Patients generally searched using a combination of search engines and specific websites. NHS Direct and bbc.co.uk were frequently cited by patients. In addition, one patient displayed great enthusiasm for a website about valve replacements:

> *There's one site I go to I have got in my favourites, valvereplacement.com. It has been brilliant, but that is for people who have had valves replaced. You can write in or ask questions, you can learn lots of questions like that. There's more information based sites which you don't interact with (P11, P1).*

Patients described using other websites that were stored in their favourites, yet generally patients could not remember the name/source of the website. Overall, searching strategies were similar according to practice, gender and age.

Proficiency

Staff were generally confident in their computing skills. All were self taught and had not received any formal training in using the internet. Nurses from each practice were slightly hesitant about their internet skills and sought help from others when needed.

I actually have to search until I find it, and if I can't I'd go and find somebody else who'd give me a hand. There are a couple of nurses who can, there's one nurse in particular who's done a lot, and she's done the degree. I'll ask Nurse A, or the nurse practitioner, people who are more au fait with the computer (Nurse 2, P1).

A fifth of internet users were reliant on others as they did not always have the confidence to search on their own. A reliance on others could have implications for the type of searches that they conducted as a person may not feel comfortable accessing personal information about their health while in the company of others.

Personal proficiency at using the internet was frequently portrayed in a negative way. Terms such as *'I am ashamed'* and *'absolutely hopeless'* were used to describe internet skills. Patients described getting into a *'muddle'* due to the vast volume of information. Those from older generations expressed a sense of failure when comparing their own limited capacity with the skills demonstrated by children.

Yes, we do have (access to the internet), but I am ashamed to say that I am computer illiterate. I have my grandsons and my sons who are into it and if I ever want anything they would do it for me. When I retire...I might have a dabble at it (PT18, P1).

The survey data showed that most internet users had used it for about a year, so patients had some, but not extensive, experience of the internet (p 122). A minority were comfortable with categorising themselves as experienced/proficient users of the internet. These users were mainly from Practice 1. This categorisation was often coupled with a disclaimer that they may not always conduct a successful search.

Well, it depends what level of experience you're looking at really, I use it on a daily basis I suppose I use it at work as well, obviously it's like anything else the more you use it, the better you get at it, and you tend to know where you're going and what you're looking for. Then again there are probably millions of things which I wouldn't know how to do compared to other people (PT26, P1).

Limited proficiency did not appear to be a deterrent for using the internet. Only a small minority of patients who had access to the internet did not use it due to limited ICT literacy. Those with limited skills would enlist the help of others to assist them, or ask them to conduct searches on their behalf. Patients and staff with limited internet proficiency were therefore resourceful in their approaches to searching on the internet.

5.5.3 Quantity of information

Staff remarked on the sheer volume of health information they encountered on a daily basis. GPs in particular appeared to be in a state of information overload. One GP provided an example of the variety of information sources they received on a daily basis:

> *We're bombarded with so much information in terms of paper from you know, the Welsh Assembly, from various drug companies, from NICE and from Health Authorities, Committee for the Safety of Medicines and so on. You know we get these multiple bits of information through every day and I think it's a challenge really to try and keep up on top of this and actually have all this information in a relevant and easily obtainable sort of form and ideally in a way that isn't on paper, because if we're going to be rummaging through lots of paper to find it (GP1, P1).*

The quantity of information was a greater issue when using the internet in comparison to other sources. Patients felt *'bogged down'* with the amount of information on the internet. This expanse of information was described as *'reams'* or *'pages and pages'* from *'thousands of websites'*. Practice staff expressed particular concern for patients who encounter irrelevant information which they may have difficulties filtering through.

> *If anything there is too much information and therefore you have got to be very specific, otherwise you would end up with 2000 references and sorting out what you actually want from there can be very frustrating (Practice manager, P2).*

There were similar concerns about managing information according to the searching strategies employed (p 144). Patients highlighted the importance of *'picking and choosing'* or *'filtering'* information from the internet in order for it to be a meaningful activity. Although they were aware of the importance of appraising information, they did not necessarily have the capacity or skills to filter out information.

Women had greater concerns about the quantity of information and were more overwhelmed by the volume of information than men.

> *Um, I suppose you can get too much information if that sounds silly. You are bombarded from all sides and then think well where do I go from here, but apart from that I think it is a very useful tool as long as you know how to use it and what you are looking for (PT24, P1).*

> *I don't think I would have got the information I required. I have got very little patience unfortunately, I haven't got the patience to sit down and go through pages and pages of information to get the thing that I need I try to get the information as quickly and as easy as possible that's why the internet is really good (PT33, P2).*

Just over half of patients from each practice discussed the breadth of information on the internet. Younger patients talked about the mass of information on the internet more than older patients. Two thirds of those aged 25-54 made reference to the large quantity of information compared to just under half of patients aged 55+. It may be that younger patients spent more time online or searched more frequently than older patients and so retrieved more information.

5.5.4 Understanding

Practice staff generally understood most of the health information that they accessed from the internet. They were more concerned that patients could misinterpret, or be scared of what they encountered. The quality of information

accessed was a central issue, particularly as the internet is unregulated. Even if the information was of a high quality, much of it targeted health professionals and so patients could have difficulties grasping medical terms. Patients were also conscious of the difficulties understanding information due to the use of medical jargon.

> *It depends what site you go on. The specific ones, they go into a load of jargon and it's just like gobbledy gook but there are some ones which condense it into English, you can actually understand what's going on (PT26, P1).*

> *There was a lot of contingent information which I didn't have the answers to and it was reliant on perhaps medical information. It wasn't in layman's terms as far as medical information is concerned. I found it didn't offer anything helpful (PT10, P1).*

In contrast, other patients preferred information intended for health professionals as they were given the whole picture, rather than feeling that information was being withheld from them. However, a common complaint by patients using the internet was that some of the advice was conflicting, or confusing.

> *She said that there was lots of information on the internet but she just went round in circles with it, you know there was nothing conclusive she didn't feel that it was really of much help. Yes there was some conflicting information on there (PT27, P1).*

> *Well you see that's where sometimes when I think the internet can be a bit dangerous can't it, because the GP is telling you one thing and maybe the internet, I think it's a good thing, but it could be telling you another (Receptionist, P1).*

These issues could be partly intensified by the amount of information available (pp 148-49) which made it difficult to determine which information applied to the individual patient. Patients had a greater understanding of information from websites that targeted a patient audience. Self-help groups were described as a useful resource as patients had the opportunity to share experiences:

I think I might have logged on to a couple that seemed to be help groups, people that had experienced something similar and that of course was written much more in layman's terms, because it's written in layman's terms you don't know who has written it, you don't know how much you can rely on it (PT6, P1).

Patients preferred websites with a consumer approach, which were not only written in layman terms, but also addressed issues that in some cases health professionals would find more difficult to relate. These could even be issues that were not of medical concern, but had social implications, for example benefit entitlements.

Internet users from Practice 1 discussed understanding of information more than those from Practice 2. There was a notable difference between the men in each practice. The majority of male patients from Practice 1 discussed understanding internet information whereas only 1 male from Practice 2 discussed these issues.

5.5.5 Trust

There were uncertainties about the overall quality of internet information, particularly the trustworthiness of using the internet for health information. There was widespread concern amongst patients and health professionals about the extent to which patients relied on the information. Terms such as *'bogus'* or *'phoney'* were used to characterise some internet information. There were also reservations about the legitimacy of the information.

I think you have got to be very careful on there because there's a lot of stuff on there that's probably phoney, perhaps you get something wrong on there so that's quite important in your health (PT25, P1).

As you say anyone could put anything on there, so it might not be fact, it could just be fiction you get bogus people putting this that and the other down (PT39, P1).

With the exception of those patients who asked their GP, patients were uncertain about judging whether something was trustworthy, or how to distinguish between particular sources. Staff shared the concerns about the authenticity of information on the internet, which they had to manage with their patients who brought information in for review. Patients were aware that anyone can put information on the internet, but there was less evidence to show whether this affected interpretations or use of the information.

> *Well again yes you don't know who is putting some of that information up. I would certainly look at it, but again as you say without knowing who's putting the information up, you wonder what the credibility of it is (PT10, P1).*

The readability of information was a factor when deciding which websites to examine, yet the importance of checking the source of the information was a lesser concern. There was a feeling that people take things at face value and believe that just because it is on the TV or on a computer screen that the information is accurate.

> *People are unbelievable, because it is a computer that...my husband has absolute faith in it 100%, anything that he gets off there must be correct. (PT21, P1).*

Trust appeared to be a greater issue for patients from Practice 2, with two thirds of men and women discussing the difficulties of relying on internet information, in comparison to only half or less from Practice 1. There were minimal differences according to age and the trust placed in internet information. One way in which patients could check the trustworthiness of internet information was to compare it with other sources. Patients liked to discuss information during consultations if they had any concerns, yet it was often difficult to access health professionals to have these discussions (pp 161-64). As the internet is unregulated it is problematic for patients to overcome concerns about trusting information on the internet.

5.5.6 Internet trends

Staff and patients highlighted the increasing role of the internet as a form of communication. The internet was linked more widely to use in the NHS, rather than as a source of patient information. The majority of staff referred to e-mail as a form of communication that was viewed as a convenient and efficient means of exchanging information. There were reservations about patients communicating with their doctor by e-mail due to the lack of face-to-face contact. In traditional or telephone consultations the doctor has direct contact with the patient, whereas an e-consultation would pose the risk of missing vital signs. There were also concerns about the confidentiality of information and the possibility of overlooking e-mails from patients which were part of a general list of e-mails.

> *We are a little bit hesitant about (e-mail) its use with patients, partly because we have concerns about, first of all the confidentiality of it if they are dealing with confidential medical issues. Secondly, it doesn't put you into position where you are necessarily familiar with the whole picture, as you might be in a consultation or even a telephone consultation (GP1, P1).*

A practice nurse described the lengthy process of conducting a referral, which could be conducted more quickly using an internet based system:

> *It's like some of the referrals....so much paper pushing round, the doctor gives the referral to the practice secretary, she types it, then faxes it to the hospital. It would be so much easier if it could be just like a press of a button, and also papers don't get lost (Nurse 1, P1).*

Patients also mentioned using the internet to link primary and secondary care for results and referrals. There was an awareness of the move towards electronic records, which were viewed positively, provided that the records were secure.

I would think that (electronic patient records) would be an enormous benefit....Yes if you had an accident or was taken ill in some foreign country, it would be great if all they had to do was to tap in and get all your details, oh gosh we can't give this guy whatever, because you know... it would be great (PT6, P1).

Patients felt that the future of the internet rested with younger generations who would have higher expectations when using the internet in future health care. Internet users also talked about increasing future controls over the internet and the possibility of introducing recommended or approved websites. One patient also highlighted the benefits of involving consumers when developing websites.

5.6 Using health internet information

Patients used information from the internet in a variety of ways. These included accessing information for knowledge, new treatments and self diagnosis. These findings reflect the experiences of patients' use of the internet for health. The views of non-users of the internet were included if they expressed opinions about potential use of health internet information.

5.6.1 Knowledge

Patients commonly accessed health information to supplement information gained from health professionals. Patients usually wanted information about particular conditions, such as details of medications and any associated side effects.

I looked at it because there was someone close to me died of myeloid leukaemia; I wanted to know what acute myeloid leukaemia was. Something like that happened so quickly, and killed someone so quickly (PT46, P1).

The information off the web was good, it told you what the disease actually does, it was just facts, this is...you know, it will start off as... this is how it progresses.... it is actual facts on how it would affect you (PT24, P1).

Patients generally derived personal clarification of information by discussing it with health professionals; however this was difficult to achieve in practice and so consequently they mainly used the internet in isolation from health professionals. There were concerns by internet users and non-users about possible risks of accessing even a small amount of information. The cliché *'a little knowledge is dangerous'* was introduced by numerous patients in relation to the internet.

> *I think a little knowledge is a dangerous thing, you can't just look at these things if you're not schooled in that subject, I don't think you can pick out something and say well these are the symptoms I have got, I must have got that. You have got to be sensible about these things (PT31, P2).*

> *I think a little knowledge is a dangerous thing as well, if you start to look at these things. I guess it's difficult for a doctor, because in theory someone can all of a sudden become an expert on a very, very narrow aspect of medicine, just by researching and researching that little bit. I think that's quite dangerous because you can get the wrong things sometimes. (P6, P1).*

These issues were most pertinent when a person acted on the information, for example, through self diagnosis (pp 157-59). Respondents talked about the advantages and disadvantages of accessing information on the internet. Patients and practice staff felt that some information was of a high standard and relevant to patients, whereas other sources were deemed useless. Use of the internet for supplementary knowledge was similar according to practice, gender and age (approximately half of patients). On the whole, patients preferred to be well informed and knowledgeable about their health. Only one patient claimed they would prefer not to know and avoided health information for fear of what they would find out.

5.6.2 New treatment/lifestyle

One outcome of accessing information was to adopt a new treatment or lifestyle, such as healthy eating. Over half of health internet users described the use of new treatments/lifestyles as a result of using the internet. These included a reduction in caffeine, acupuncture and taking up yoga classes. Patients discussed the information with their GP as a possible course of action for the future. All staff recalled times when patients had come to the surgery with a new treatment or cure for an existing condition from the internet.

> *Yes there was a lady who wanted a particular procedure for varicose veins, and had heard about it on radio and didn't know much about it, and I was able to look up that for her and find the relevant part on the internet (GP1, P1).*

Patients who had unsuccessful treatments or an unresolved problem were more likely to seek new treatments due to their frustration with existing care. There was an awareness of the limitations of taking action as a result of accessing information without consulting their GP.

> *I think that would be dangerous you can get people who are a bit gullible; they could take a wrong drug. If I found anything on the internet I think I would come back and refer to my GP before I would take anything (PT32, P2).*

Alternatively, some patients adopted a new treatment, or more commonly lifestyle, solely based on the information they accessed.

> *Somebody had mentioned glucosamine to me, because I have got arthritis and I did look that up..... That one I did follow through, I read all sorts of things about glucosamine, there's quite a lot about it on the internet. Both I and my sister and my sister's dog we started to take glucosamine about two years ago, when it hit the news a lot...that I find is excellent. (PT8, P1).*

Alternative therapies were often adopted as new forms of treatment. Staff frequently associated alternative therapies with the internet, whereas only one patient talked about using the internet for alternative therapies:

> *Quite a few have come along and found things off there and sort of alternative medication and things, you know they've sort of come along and said I've found this, is this ok, so they are using it yes (Receptionist, P2).*

Use of the internet for a new treatment was similar according to practice, age and gender. In summary, using information to seek new treatments further reinforces the shift towards patients engaging in more self care and taking responsibility for managing their own health.

5.6.3 Self diagnosis

Internet information was used by patients to self diagnose an illness or confirm symptoms. Health professionals highlighted the importance of considering information in the context of the individual, as a patient may encounter information that does not apply to their particular situation.

> *A high cholesterol on it's own for example, may mean nothing for somebody who's otherwise perfectly fit, but if you've got it with hypertension, cigarette smoking, lack of exercise, family history of diabetes, being over weight, getting on a bit in age and so on, all these things. If you build all these things into it, then the health professional is better able to actually formulate what sort of risk that cholesterol level has for a particular patient, which the patient would find very, very difficult to actually determine on his own (GP1, P1).*

There were concerns that patients would be scared by the information on the internet, for example, they could conclude they had a serious disease.

> *Wouldn't it frighten a lot of patients if they found out certain information? They can get the wrong end of it, or they completely misconstrue everything that they've read, but then that's when they need to come to discuss it (Nurse 1, P1).*

I was reading the side effects of ECT and that some doctors had said it was akin to having brain damage, you know and finding that is quite scary. You think oh golly am I brain damaged you know? Yea, I mean I think a lot of the articles were for health professionals you know and I am not a psychiatrist and so I was looking at it from a patient's point of view. And you approach things differently don't you (PT1, P1).

Internet users and non-users talked about the potential of conducting a self-diagnosis as a result of accessing information. Self-diagnosis was viewed as a risky process, with the possibility of serious consequences.

It is a concern because none of it is guaranteed, anyone could go on to the internet and put all this information on it and it could actually kill people, they could say I have got a pain there I'm dying of cancer and they go and pop themselves off (PT36, P2).

So if you mean am I going to buy a magic tin of beans off the internet, no I'm not! I am not going to buy any quick fix, I am just going to take an aspirin and stagger in here and see what's going on. In preference to doing my own interpretation and thinking I'll be able to cure this, if I inject myself with...this....it's not going to happen with me, I just wouldn't believe it. There are all sorts on there (PT16, P1).

These examples illustrate some of the more extreme comments about the possible drawbacks of using the internet. Similar patterns were found according to gender with half of men and women discussing use of the internet for self diagnosis. There were six cases where patients self diagnosed a condition by using the internet. These included polycystic ovaries, deep vein thrombosis, Fibromyalgia, thyroid trouble, a lump following an angiogram and Osgood-Schlatter disease. With the exception of one patient, all self-diagnoses were from Practice 1. Less than a third of all patients from Practice 2 talked about the issue of self-diagnosis in comparison to two thirds of patients from Practice 1. A patient from Practice 2 described the similarity between the information accessed on the internet and her own experiences of diagnosing Ffibromyalgia:

I read through one particular site and it listed symptoms, I took one look at the list of symptoms and thought, my God that's me, it just sort of stood out like a sore thumb, so to speak (PT43, P2).

Another patient described a side-effect following an angiogram. Despite seeking initial advice from health professionals, the patient eventually self-diagnosed the problem by accessing information from the internet.

Afterwards they were very careful that I didn't get any extra bleeding under the skin and everything healed up, then I developed a lump and I had heard if you get a lump you had to go back to your doctor. I kept coming back here generally being a pain in the neck I suppose. I phoned the ward and they said it's nothing to do with them and then I read on the internet a couple a weeks ago, after an angiogram it's quite normal to get a small hard lump. Nobody else had mentioned it (PT11, P1).

Both of these cases were followed up with a visit to the doctor for clarification and so were not dealt with in isolation. An element of danger was expressed in actively looking for things that could be wrong. Self-diagnosis was associated with tendencies of hypochondria, which was claimed to be an *'unhealthy'* path to take.

Sometimes I'm quite sure people do think they have things they don't have, simply because you follow through on the leads and you think oh well I might have that. You do have to be careful, or you'll find you've got the plague {laugh} (PT8, P1).

Yes I think it would depend on the personality, you could easily think that....I have got a friend who's got everything Motor Neurone disease, you name it; really she hasn't got any of it (PT50, P1).

Despite the move towards patients taking more responsibility for their health, patients in this study were generally wary about taking on too much responsibility by self-diagnosing conditions.

5.7 Patient-centred care

The role of health information in enabling more informed patients was a central issue for patients and staff. The impact of accessing information raised a variety of topics during the interviews, such as an increase in patient autonomy, the impact on consultation discourse, conflict and views about face-to-face contact.

5.7.1 Patient autonomy

Health professionals described a shift in how patients perceived their own role in health care. Patients were more informed and interested in their health, resulting in raised expectations. Staff were generally positive about the more informed patient who took on greater responsibility for their health:

> *I don't think it's a bad thing, at least they're interested. They are taking, a sort of an interest in their own health, or what they're actually taking and then it gives you the opportunity to go through it and alleviate any fears that they may have (Nurse 1, P1).*

> *I know that some of my colleagues would probably fear that they (patients) are armed with more information. Patients want the best deal, so I expect them to have the same expectation and we try and improve our services, so that at the end of the day they are happy. I see that as not a threat but a positive outcome (GP, P2).*

Patients prepared for consultations by compiling a list of questions they wished to address. Pre-determined questions were used to direct the consultation towards these key areas. Informed choice was emphasised by the majority of health professionals as a way of providing patient centredness.

> *Yes I think there are benefits; it probably gives people more of a choice then, they know what they are letting themselves in for, they know what's going to happen and what's not going to happen, it all just depends on the person how much you want to know really that's the thing (Nurse, P2).*

Patient centred approaches in consultations, such as shared decision making, are an increasingly important feature of health care (Elwyn, 1999). Some patients felt more in control when they accessed information and highlighted the need to further empower patients. One way of increasing control over decision-making is by accessing health information. Patients talked about the importance of self help by monitoring and managing their own health, and only seeking advice when necessary.

> *I think very often one's health is in one's own hands to some extent, you're the one doing it day to day or whatever, I don't rely too much on the health profession. I think people feel let down in their day to day health and they are looking for themselves at these sort of things, trying to find out what they can. I don't feel supported when I come up here (GP surgery); there's no support for me (PT23, P1).*

Self help was considered important for both the individual, but also to help relieve the burden on the doctor. Patients supported the move towards a greater accountability for their own health, for example by taking a greater by interest or more independent outlook on their health. Informed choice was a key ingredient for patients to assist patient-led decisions. The availability of appropriate health information therefore had an important role in promoting informed choice.

Issues of patient autonomy were considered more by patients from Practice 1 with half of patients discussing the role of information in promoting autonomy compared to only a third from Practice 2. There were few differences in views about patient autonomy according to gender or age.

5.7.2 Consultation discourse

Many patients liked to discuss information they accessed from the internet, or other sources, during a subsequent consultation. The majority of patients from each practice had discussed information sources generally at some time during consultations. The consultation was therefore used as a means of verification.

Patients needed *'clarification'* or *'advice'* and a general assessment of the information by a health professional.

> *I think that they (GPs) try and put people's minds at rest. Obviously if someone has found something in the paper and they are a bit worried about it, then it helps to discuss it, because it could be something in all innocence that they have picked up that is not relevant at all...I think that they do help to put your mind at rest and take on board what you are saying, which I think is great (PT2, P1).*

Patients sought *'peace of mind'* by discussing issues they encountered when accessing health information. Patients felt more prepared and experienced an increased degree of control in consultations when they introduced information:

> *I think I felt I was taking more control, which to me was quite important, um you know taking more decisions and not being treated like the patient. Which I think very often health professionals do, subconsciously probably (P1, P1).*

Health professionals highlighted the value of discussing information patients had accessed, but found it difficult to manage due to the heavy demand on time. One GP reflected on their personal beliefs about supporting patients, but then described the reality of practice:

> *Oh indeed, I personally feel if patients come along with something you do need to give them the time and understanding and see what they have brought along.. often these letters.....Oh yes if we had more time we could listen to whatever the patients brought in, you don't have the time, I'm glad that most of our patients don't bring it along because of the number of patients that we see (GP, P2).*

GPs were generally content to discuss information, whenever possible. This view was mirrored by a small proportion of patients who recounted personal experiences of a facilitative style by GPs in consultations.

Yes, I would have no hesitation if I had seen something to raise it as a query, it wouldn't worry me just to explore...yes, my experience has been good here, particularly if ever there has been a question or what are the other options (PT10, P1).

If I said I read this on the internet they would be quite happy to discuss it with me (PT33, P2).

In contrast, other patients chose not to discuss information in a consultation as they found it difficult due to time constraints and a fear of challenging the doctor (pp 164-65).

So yes, they are very amenable the doctors and they will talk to you, but you are conscious of the fact that there are people waiting outside so I would be rather specific, or I would be very careful when to do it (PT31, P2).

The survey demonstrated that patients used the doctor most frequently for health information, yet factors associated with the consultation, such as time constraints inhibited this process. Consequently, some patients chose not to discuss or introduce information sources in consultations.

I just find I had a consultation last week with the doctor and she was running late and I felt like I have got to get out quick, because as I went in she was like I am running late, 40 minutes and I was like oh right and half the things I wanted to ask I didn't ask (P15, P1).

I think it all boils down to time, if doctors had got time I think they would take it on board, but then you don't want people coming in with a big thick journal, oh you know I have read this and that and the other. So it is all about time, it would be good if you could go somewhere, if there was a drop in centre type of thing because GPs are hard to get hold of (PT39, P1)

Patients described occasions when they had accessed health information which warranted a discussion with a health professional. However, they did not feel this

was sufficient reason to consult their doctor. Consequently, their health information needs were not met. Discussing information during consultations was most important when something was new, for example a new drug or treatment for an existing condition. There were also issues about self-diagnosis as patients made suggestions about a potential diagnosis to their GP. Introducing these issues was handled with caution, as they did not wish to challenge their GP by offering their own assessment (pp 157-59).

Patients were reluctant to actually produce the information they had accessed. They were more likely to mention that they had looked for something, than to take the information into a consultation.

> *I haven't actually brought it (information) in and laid it out and said should I be having this? (PT16, P1).*

> *People say they have had a look at an operation on the internet, you know they put it up on the internet, the whole operation have come up on it, they haven't brought it in but they've told me they've actually done it (Nurse, P2).*

A third of patients from Practice 1 referred to bringing information into a consultation, yet no patients from Practice 2 talked about personal experiences of using this approach. All staff recalled times when patients had brought information into a consultation. Information was mainly from magazines and newspapers and printouts from the internet. Generally, bringing in internet information was not a frequent occurrence, but staff felt an increasing number of patients were adopting this style of consultation.

> *Yes, but that's rare, not so common as like some of my colleagues elsewhere, they say they get sheets of paper being printed out from the internet and they bring it along, so you spend time reading all those things (GP, P2).*

5.7.3 Conflict

Patients were concerned about how health professionals perceived patients that were knowledgeable about their health. Some patients felt it was inappropriate to introduce new information to a health professional, regardless of the circumstances:

> *No I wouldn't, because I would think that the professional would always know more than I did (PT3, P1).*

> *Personally I would reject that idea because the GP is trained, he should know what he's talking about so I put my complete trust in what he tells me (PT 32, P2).*

Others wished to discuss information, but were reluctant to do so as they did not want to offend the doctor.

> *I think you have to be careful because you don't want to cause offence to doctors because for years they have been regarded as God. I don't want to be critical but I think some of them find it hard to take another opinion especially from a patient (PT11, P1).*

> *I think they don't like it, they are not interested in your views I find. I would like much more help to stay healthy and be advised, I would like to live as long as I can and I'd like to be on that premise advised and helped in that way (PT23, P1).*

A few patients highlighted the limitations of GPs, who as generalists did not have detailed knowledge on all topics. This potential lack of knowledge was viewed as an even greater challenge in cases where the information was very specialist. These patients believed that GPs would react negatively when confronted with information sources, as it could challenge their role. This view was often an assumption made by patients about how they felt their doctor would react, rather than personal experience of such hostility. Health professionals were positive about patients being informed and were happy, in principle, to discuss information brought into consultation. In practice, issues such as time constraints

prevented them facilitating this request. Staff and patients acknowledged the difficulties of managing information in consultations:

> *Well that's as far as it went because I felt uncomfortable about it, as soon as you mention the internet, it was like non-response which made me feel uncomfortable, so I thought I'd better shut up (PT43, P2).*

> *Well, not dangerous as such but I know one doctor got a little bit annoyed because I think it was two patients had come along... I've got this disease and I need to be referred to a rheumatologist, whereas actually maybe they didn't need to be, do you know what I mean? So they are telling the Doctor what's wrong with them before they come in (Receptionist, P2).*

In contrast, some patients depicted a receptive approach from health professionals:

> *They have been very interested actually; I don't suppose they have got time to look up everything. I have printed stuff off and they have sat and read it.. can we have a copy of this and put it on your notes, the ones that I have seen have been receptive (PT49, P1).*

Health professionals were fully aware of the extent to which patients seek information in addition to that received in consultations.

> *I think a lot of patients feel embarrassed to actually admit or come clean about having researched things and certainly I get that feeling from some patients. I don't ask about it, I don't usually ask them what sort of information they've had already and when I do I do get that sense of embarrassment sometimes. Oh well I have actually looked it up and so on, it's almost as if they feel that I might be taking it as an insult, that they've already distrusted me by looking it up (GP1, P1).*

There were varied experiences about conflict when discussing patient information with a professional; however there was strong consensus from patients from each practice about the difficulties of managing this conflict in the context of primary care.

5.7.4 Face-to-face contact

The importance of having a face-to-face interaction was valued by both staff and patients. The loss of face-to-face contact was considered a detrimental consequence of the proliferation of sources such as the internet.

> *Unless you actually see someone face-to-face you are not going to get all the right information from the person, so I don't think it would be good sense in that way. But for the information side of it would be great (PT2, P1).*

> *There is a place for computers but I think it's taking away social skills. I don't know how people interact, I think that's the reason we have got a lot of problems these days, there's no sense of social interaction that goes on, people are there in one form or another sat in front of a bloody computer (PT50, P1).*

The ability to ask questions and gain clarification was also a valued aspect of face-to-face contact, something which sources such as the internet did not seem to offer. In contrast, the internet was used as a method of reassurance to prevent patients from worrying that they had a particular condition. Using the internet therefore sometimes aided patients in their decision of whether to consult their GP:

> *Sometimes like me I have got a pain, it could be stress but you think of cancer a lot of people start worrying their heads off, rush down to the doctor they panic, but if it's got it on the internet where people can see it, don't panic about it, it could be this it could be that, it would be helpful to a lot of people (PT36, P1).*

Patients generally felt that a person who consulted frequently would be perceived negatively by their doctor. They needed to justify that they only consulted a doctor when it was really necessary. Deciding to consult was therefore rationed to occasions when things were serious. Patients were again defensive about their consultation patterns, claiming that they only accessed the doctor if they felt it was something genuine (p 138).

I feel embarrassed when I come because I feel I come too often so I don't like doing it, but then I think it is ridiculous to ignore it, I will go, I will apologise and come in and get out as fast as I can but I will go (PT12, P1).

Patients were very careful to avoid wasting the doctor's time. They would therefore save everything up for a consultation and only really consult for urgent things, or for persistent ailments.

I think I don't come because I know I have got to wait and having two kids you just can't do it. And I save everything up then (PT15, P1).

I think probably if I was going to my GP because I felt unwell or because there was a problem then I would ask them about it, if it was something where I didn't need to actually bother my GP because their time is very precious then I would try to do as much research myself. Maybe if you needed to go the GP you can say well this is what I've done this is what I've found out so far (PT49, P1).

5.8 Summary of main findings *(Study objectives 1 - 4)*

Approaches to information seeking

Patients mainly adopted an active approach to accessing health information about specific illnesses. Passive discovery was widespread, but was less likely to have an influence on patients, due to the perceived lack of relevance. Patients also acted as intermediaries by searching for information on behalf of others. This type of searching was predominantly conducted by women and patients from younger age groups.

Managing the internet

The majority of respondents had some form of access to the internet, either direct access, or access through others. The internet was commonly used to seek information about health issues. Patients used a combination of search engines and websites to find information. Search engines were used commonly to gain information, despite the volume of information they retrieved. Staff and patients reported an average proficiency of using the internet, with few experienced users.

Patients experienced 'information overload' and found information from the internet difficult to interpret due to conflicting advice. These issues were of particular concern for women from each practice. Patients valued the internet for health information, but some questioned the trustworthiness of information. Patients from Practice 2 were more sceptical of internet information than those from Practice 1. In general, the internet was viewed as an increasingly important resource for the delivery of future health care.

Using health internet information

Patients mainly sought information from the internet for knowledge about health issues. The internet was used to supplement information received from health professionals. It was acknowledged that a little knowledge can be dangerous. Information seeking sometimes led to a new lifestyle, or suggestions for a new treatment. A decision to adopt a new treatment or lifestyle based on internet information was usually discussed with a health professional. Self-diagnosis was widely viewed as a potential use of the internet. A small proportion of patients (predominantly from Practice 1) used internet information for self diagnosis, but most felt this was a risky activity.

Patient-centred care

Accessing health information provided greater patient autonomy for their health. Taking more of an interest and increased role in their care resulted in more control for patients. Health professionals supported a rise in patient responsibility for their own health care. Patients wanted to discuss information with their GP. Although patient involvement in their care was welcomed, it was difficult to attain in practice. Patients had varied feelings about potential conflicts in primary care, yet valued discussing information during a consultation. Time was the biggest constraint in general practice, which impacted on the use of consumer health information in consultations. Patients were happy to mention information sources during consultations, yet they were reluctant to produce the information. In general, patients value interactions with their GP, but felt an overwhelming need to justify their decision to make an appointment for a consultation.

CHAPTER SIX

FINDINGS OF THE DISCUSSION FORUM

6.1 Introduction

This chapter presents the findings from the online discussion group which was set up to gain perspectives about consumer e-health. Given the localised nature of Phases 1 and 2 which were carried out in South Wales, an online discussion forum offered an appropriate and innovative means of gaining much wider perspectives. To date, there has been limited use of online discussion fora as a means of collecting data. This forum aimed to meet the final research objective by exploring national and international perspectives on the use of the internet in primary care.

The first section of this chapter describes use of the discussion forum, including a profile of forum participants and trends in forum use. The second section comprises a narrative account of the discussion threads from the forum. The final section reports the findings from an online evaluation of the discussion forum. The role of the researcher as the moderator of the forum is also examined.

6.2 Use of the forum

The most common reason for not participating at all in the forum was non-response to the invitation (14%, n=12). Other reasons for declining to take part included one respondent who was changing jobs and another who felt that the subject area was not relevant enough to their field of expertise.

Recruitment to the forum resulted in a total of 73 participants (pp 74-76). Use of the forum was categorised in a number of ways. Participants could add new discussion threads, reply to existing threads, or merely browse the forum without making a written contribution (lurking).

Table 6.1 provides details of the total postings and readings of each thread at the end of the discussion forum. Participants were informed at the outset that they could post new threads, however most appeared reluctant to do so. Relatively few threads were posted on the forum (n=6); half of which were introduced by the researcher[1]. The remaining new threads were posted by three different participants from the UK and the USA.

Table 6.1: Forum postings

Thread	Date posted	Replies	Views (browsing)
1. Views/experiences of patients' use of the internet	20/1/04	8	234
2. Patients with internet information in consultations	21/1/04	13	164
3. Internet use by isolated patients	30/1/04	3	82
4. Patient experiences of the internet	10/2/04	2	57
5. Online information for children	17/2/04	2	55
6. Future developments of the internet	4/3/04	4	39
Total		32	631

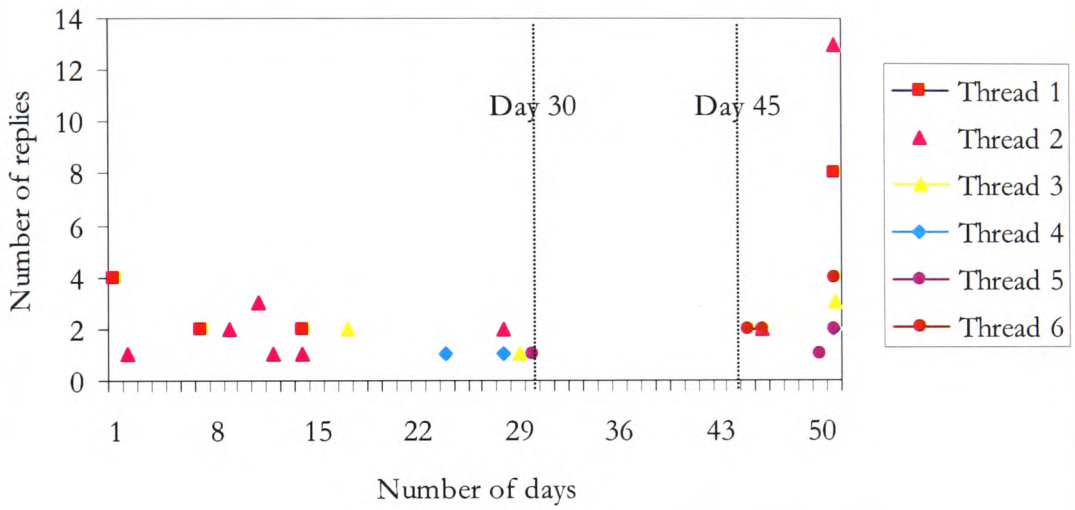
There was greater activity in the number of replies (n=32) and viewings of the forum threads (n=631) than posting new threads. The initial threads received the highest number of postings and views; however activity on these threads decreased during the latter stages of the forum. This type of activity is consistent with the use of discussion fora, as participants are often more comfortable browsing the forum rather than adding their own comments. It was made clear to respondents in the terms of reference that the discussion forum was for research purposes. Due to the nature of the topic area, it is likely that the discussion forum sample were members of other discussion groups. Consequently, they may not have viewed themselves as research participants and so were less motivated to contribute to the forum.

The number of replies posted on the forum decreased over time. Figure 6.1 reveals that the majority of postings were made during the first 30 days (n=25). No postings were made during days 31-44, but 7 postings were made in the final week

[1] A default username of 'supervisor' was adopted by the researcher for the purpose of making contributions to the discussion forum.

of the forum (days 45-50). The postings during the last week of the forum were made in response to a final thread from the researcher prompting respondents to contribute before the forum closed (day 42). It was originally intended to keep the forum open for 4 -6 weeks, depending on activity. The participants were informed when the forum was due to close, however it was kept open until the end of March (65 days) to account for any late postings. There were no postings or views made after day 50 of the forum, which was taken as the cut-off point for data collection.

Figure 6.1: Replies to discussion threads



Fifteen people (21%) posted threads and/or replies on the forum. The number of responses was well distributed among the fifteen respondents ranging from 1-6 responses per person. The majority of these contributors were health professionals and academics from the UK (Table 6.2). This distribution was not surprising as the topic was likely to be of greater relevance for UK participants. Stakeholders from the UK also comprised the largest proportion of the sample group. Academics (60%) accounted for a slightly greater proportion of the contributors than health professionals (40%). Male contributors (60%) also outweighed women (40%).

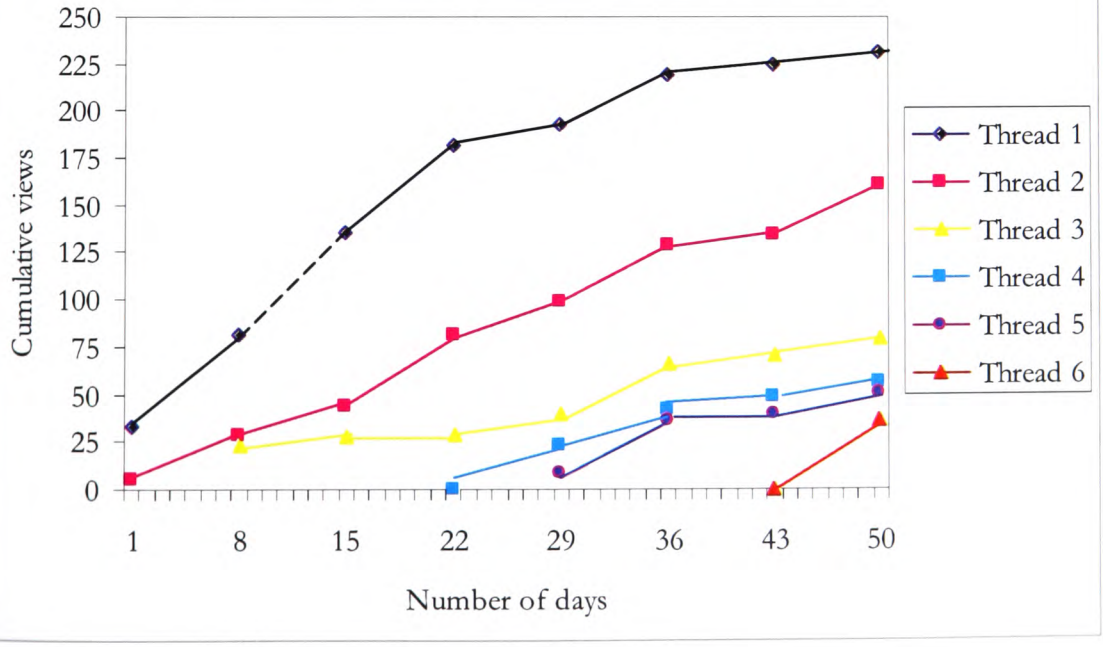
Table 6.2 profile of contributors

Discipline	Replies	Gender	Country
HP 2	6	M	UK
HP 5	5	M	USA
Acad 6	3	F	UK
Acad 1	2	M	UK
Acad 3	2	F	UK
Acad 2	1	M	UK
Acad 4	1	M	UK
Acad 5	1	M	UK
Acad 7	1	M	UK
Acad 8	1	F	USA
Acad 9	1	M	Finland
HP 1	1	M	UK
HP 3	1	F	UK
HP 4	1	F	UK
HP 6	1	F	Germany
Supervisor	*4*	*F*	*UK*
Total (n=15)	**32**		

HP = Health professional Acad = Academic

A greater degree of activity was demonstrated in the number of discussion forum viewings. Figure 6.2 shows browsing activity by thread at the end of each week.

Figure 6.2: Browsing activity by thread



Each point on the scale represents the total number of views accumulated during the life of the forum. Respondents had the opportunity to view the forum as frequently as they wished and so may have viewed the postings on more than one occasion. This explains why the viewings of the first three threads exceed the number in the forum sample (n=73). The highest viewings per thread occurred during week two, with 55 views of Thread 1 (see dashed line on Figure 6.2). Overall, browsing activity was busiest during week five (day 36) with a combined total of 136 views for all threads. Interestingly, no postings were made on this day.

Two main strategies were adopted by the researcher to maintain interest in the forum. These included a weekly reminder e-mail to all participants and a topic watch facility which sent automated e-mails to participants when a reply was posted on the forum. Users had the option to switch off this facility if they felt inundated with e-mails from topic watching. It was not possible to monitor how many participants chose to use this facility.

Overall, use of the forum was fairly low; however a number of interesting issues were raised in the comments posted on the forum. These are presented in the following section as a narrative account.

6.3 Narrative of discussion threads

6.3.1 Views/experiences of patients' use of the internet (Thread 1)

Participants were introduced to the forum with a standard thread provided by the researcher. Appendix 12 provides a screen shot of the introduction, which included a general question to solicit views about patients' use of the internet. Within a few hours of launching the forum the first respondent offered a series of comments about why patients used the internet for health information:

Internet access is now widespread in the UK (is this board just about UK patients?) and the third most searched for topic is health - showing there is a major unmet need - perhaps this is because current healthcare systems do not make the information available in a form that they can use/remember OR *patients are unwilling to ask face to face (particularly about personal issues)* OR *they want to be able to refer to information at a time and place that is convenient to them* OR *they want a free second opinion.....The quality of health related information on the internet is poor (although improved from a few years ago) and often doesn't meet latest best practice guidelines, isn't maintained or is of dodgy provenance (fom200).* [2]

These ideas focus mainly on unmet needs in current information provision, which accounted for the increasing number of patients who seek health information. There were also remarks about the growing concern of the quality of information on the internet, a well established area of research in health information (pp 38-39). A series of replies to the above posting highlighted that although quality is a concern, patients have a number of coping strategies to overcome such difficulties. In addition, quality was not perceived to be only associated with the internet, but was considered an important consideration for any type of health information.

There was a desire to move away from the quality debate, which one health professional claimed had dominated research in recent years. Focusing on quality issues was described as an 'obsession' in field of consumer e-health. Another participant felt that in contrast, the amount of good quality information had also increased, including that provided by specialist health professionals. Participants felt confident that patients would adopt a number of strategies to avoid potential risks, for example, asking others to verify the information.

In addition to gaining factual information, reference was made to patients' use of the internet to share experiences with others. Due to its interactive nature, the internet was considered to be an effective medium for these discussions.

[2] Postings from the discussion forum are reported exactly as posted and are referenced with the username provided by the researcher.

(Point 4) The net provides a wonderful opportunity for ordinary people to publish and read personal experiences that are by definition not evidence based (Kam200).

Sharing these experiences was viewed as an important way for patients to validate their experiences. It may be that greater value is placed on personal experiences from a patient perspective than an objective viewpoint from a health professional. Quality of information was therefore less important in this context as patient experiences are of a subjective nature. One participant backed up their comments with their own research findings:

I particularly agree with point 4 {see Kam200 above}. People use the net not just to find out factual information but to hear about other people's experiences. This is the finding from my qualitative research with mental health users and I know that other researchers are finding the same (bal100).

There were greater concerns about the relevance of information. Regardless of the quality of information, patients posed the risk of applying irrelevant information to their individual situation. This issue highlighted the problem of the generalist approach to information on the internet, which is non-personalised. For example, two respondents referred to patients who had brought in details about treatments from the USA, which would not be supported by the NHS.

6.3.2 Patients with internet information in consultations (Thread 2 and 4)

Forum participants noted the increasing trend of patients acting as intermediaries by distributing health information to others (pp 138–9). Health information received by the public may therefore often be unsolicited. Although in many cases the information may be valuable and welcomed by the recipients, respondents commented that others may feel overloaded with information that they had not requested.

A popular issue for discussion was patient use of information during consultations. Although a thread about this topic was initiated by the researcher, it appeared in nearly all of the other discussion threads. One GP described the advantages of searching online with patients during consultations, only really having difficulties due to a difference of opinion:

> *The people with whom I have had more difficult consultations have been people whose explanatory models and world views were already different from mine; who had previously used written materials or the opinions of other "health specialists", herbalists and spiritualists for example (gam100).*

Whereas others described the *'dreaded internet printout syndrome'*. There was a general consensus that discussing information accessed from the internet during consultations could challenge the health professional, whereas in other situations it may challenge the patient. One health professional described their experiences of dealing with inappropriate requests from patients:

> *For those of you with experience of patients bringing information to the consultation, have you ever come across this dreaded 'Internet Printout Syndrome' that lots of papers talk about? We tend to find patients bringing in info. about wonderful treatments from the USA e.g. orthotics [foot realigning insoles] made of high tech. materials and at costs our NHS could not support. Often the patient who has 'researched' this is full of jargon and believes they are more informed than the clinician (elm100).*

One participant offered an account of one case where the patient won the 'game', yet in another case the doctor won. The 'game' in both cases represented a discussion about side-effects of medication.

Diabetic clinic today: the nurse had seen him and he had already been asked why he wasn't taking a statin. He came well armed and showed a sheaf of downloaded material. My opening gambit (1st game): "it is generally recommended that people with diabetes take a tablet called a statin to lower the risk of heart attacks and strokes". He pulled out his sheaf of papers: "can you name every side effect in this information I've found?" (0-15). "many of the complications are rare": "they wouldn't be on the net if they didn't happen" (0-30). "none of our patients have had any serious side effects": "if I got them, would I ever get better?" (0-40) "The side effects get better when you stop the tablets": "huh" (game to him, we agreed that there was no way that he would take them, whatever any specialist said).

(game 2) "Whilst I was surfing I came across information about homocysteine and folic acid. what do you know about it?" : "There are well established links between homocysteine levels and risk of heart attack and between folic acid levels and homocysteine levels but no research trials have shown that taking folic acid reduces the risk of heart attack. A recent paper that I read on the internet this weekend has suggested that this is because folic acid supplements are artificial and that there may be important differences between natural and artificial folic acid that means that supplements won't help you." "Oh thanks doctor" (game to me?)
(gam100)

Although such discussions may pose challenges for health professionals, a later reflection on this posting provided encouragement for the patient to take more of an active role in their health care:

I have been reflecting on my posting, made with a certain amount of feeling close to the event. This person, "the patient", has always questioned (it feels like challenged) my, the "expert", advice and opinion. The internet has given him more information and therefore power behind his questions. The stuff he had downloaded was from sites that I consider reputable; we disagreed on how to apply the information to/for him. He should have the information; after all he is the one with the increased risks who has to take the tablets (gam100).

There were also references from a policy perspective about the new 'breed' of informed patients:

> *The DOH wants patient info to be given "appropriately and timely" but that is very different for all individuals...doesn't the patient take the lead on that, not the staff? Regardless of the info source (hol200).*

Even though much support was given to the increasing number of informed patients, there were realisations of the practicalities and limitations of dealing with internet informed patients. These issues included, time to have extended discussions of detailed information, lack of relevant information, and potential challenges to advice and power. It was felt that use of patient discussion fora suggested a move towards the patient taking the lead in decision making. One contributor talked about ways in which patients have developed autonomy for decision making, often despite advice from doctors:

> *They use the discussion forums as ways of validating the decisions that they make when they go against what the doctors have advised. It has been interesting to see the people develop over the last three years. Many have become quite capable of deciding what their proper doses are (bet100).*

In this case, patients had access to expert advice from a private medical practitioner who acted as the moderator for the discussion forum mentioned in the above quote. There were however some reservations about self-diagnosis. Some websites offer a personalised approach to health information in which the patient answers a series of questions about their symptoms. However, this approach was considered dangerous territory if a diagnosis had not been previously made by a doctor. Self-management of diagnosed conditions was advocated, yet attempts at self-diagnosis were often considered futile.

> *I think that X raises a good point. It is almost impossible to diagnose over the internet. Putting a bunch of symptoms together is usually not very useful. I know instances where it has worked, but this was usually after many possibilities had been ruled out already (lew200).*

Health professionals were highlighted as an important resource to guide patients with internet information. It was acknowledged that staff needed further training to deal with the large volume of information and increasingly demanding patients in consultations.

> *Regardless of the info source, health care staff should have or be trained to have the skills in 'interviewing/counselling technique' to deal with this interaction (hol100).*

Education for patients was also important, particularly strategies for appraising health information. Given the difficulties that many health professionals have in appraising the evidence base, this is a big step to make for the general public, who may have limited knowledge of research methodology.

6.3.3 Internet use by isolated patients/children (Threads 3, 5 and 6)

Participants briefly broached the subject of vulnerable or isolated groups and their use of the internet. Evidence was presented to suggest that the biggest users of internet based resources were by people from small islands and isolated nations. Less information was available about these issues in relation to socially excluded groups in the UK and the USA. Children's use of the internet was also introduced, but this thread solely comprised web-links to raise awareness of current research in this area conducted by the author of the thread.

As highlighted earlier in this chapter, there were no postings during weeks five and six of the forum. The number of viewings continued to steadily increase, but new discussion threads were not added. The researcher therefore added a final discussion thread to gain concluding remarks from the participants before closing the forum. This thread asked participants to consider their views about important developments of patients' use of the internet in the future. Most predicted an even greater increase in patients' use of the internet. There were also concerns about the need to provide support for health professionals in primary care through guidance and clearer protocols in order to respond to the challenges of internet informed

patients. These comments mainly reinforced the issues discussed in the earlier discussion forum threads.

6.4 Forum evaluation

Following the completion of the discussion forum, an evaluation questionnaire was e-mailed to all registered participants (Appendix 13). The questionnaire was designed using an online format to enable ease of completion and analysis. The questions mainly focussed on gaining feedback from participants about using the forum. Those choosing not to contribute to the forum were asked to provide reasons for non-participation. General views were also sought about the forum design and the forum topic.

Response to the questionnaire was fairly low, resulting in only 12 replies (16%). These were mainly academics (including one student) and health care professionals. Nearly all the health care professionals were based in the UK (n=4), with the exception of a doctor who was based in India and a consultant in Israel. The remaining respondents were academics from the UK (n=2), USA (n=2), Finland (n=1) and the Netherlands (n=1).

6.4.1 Use of the forum

Three quarters of the questionnaire respondents logged on to the forum following the receipt of registration details (n=9; 75%). The main reason for not logging on was lack of time and one person had difficulties with their password. Even though a password reminder was issued by the researcher, this did not encourage the user to log on. All of those who logged onto the forum browsed the discussion threads, however, only 3 (25%) posted replies.

Respondents who had accessed the forum (n=9) were asked why they chose not to post a thread or reply on the forum. Most users (n=5; 55%) were too busy to post a

message. The remaining users were not enthused to contribute to the existing threads, or forgot their username and password.

> *I found it very interesting to see other people's views on the issue but never felt compelled to post.*

> *I only looked once- there were no topics where I had a strong opinion*

> *I did indeed joined the forum and was awarded a 'geeky' username and password which after one use I promptly forgot! I never again thought of logging in again because of this.*

The first two comments were based on personal interest in the topic area, yet the last criticised the logging on process. These comments could partly account for some of the reasons why the sample group did not log on.

6.4.2 Comments about the forum

Respondents were asked for their general views about using the discussion forum. In addition, they were asked to highlight anything that they particularly liked or disliked and to provide any suggestions for improvements. In general, the comments were positive about the idea of using a discussion forum, which was viewed as an effective way of sharing ideas. The forum was considered an overall success by participants, as postings were made from those considered as leaders in the field.[3]

> *I particularly liked the range of health care professionals accessing the discussion forum and to understand their views and experiences with the Internet.*

[3] Half (n=8) of those contributing to the forum included their name at the end of their postings.

I enjoyed reading other people's contributions and it helped me to reflect on my own experiences. It was my first experience of such a forum. I have now joined another forum and contributed to that too.

There were however a series of comments about the barriers to participation, predominantly in relation to a lack of engagement and issues about accessing the forum.

Use of cookies so that people can forget their password and still get in.

I thought the forum was great; it was really professional and easy to navigate. Perhaps reinforcing the importance of participation either by email or at the forum may have encouraged greater contribution to the discussion. But overall I thought that the group was very successful.

Using cookies to store passwords was suggested as one way to encourage participation[4]. The use of cookies was explored in the pilot, but was not available. A weekly e-mail summarising the key topics was proposed by two participants as a way of prompting access and responses. Some considered use of the forum to be limited as people appeared to contribute and then leave the forum.

The forum provided a novel and effective way of generating discussion. Recruiting the sample for the forum was not a problem as many people were interested in the topic and were enthusiastic about taking part. Due to time constraints and a lack of engagement many users did not contribute their views to the discussion. This type of non-use is consistent with general use of discussion fora as the number lurking on fora far exceeds those who post. Although this discussion forum was clearly intended to be a source of primary data, many of those registered may have behaved in way in which they were accustomed to in other fora and so did not have a motivation to post their views.

[4] Cookies send data from a server to a browser to identify the user.

6.4.3 Future of patients' use of the internet

The final question in the evaluation survey asked respondents to predict how patients' use of the internet would develop over the next ten years. Nearly all respondents envisaged a big increase in patient use of the internet. This increase was not solely related to number of users, but also frequency of use and interest in using the internet.

> *It will increase considerably and I am sure will benefit people/patients/carers and clinicians. Web sites will have to be kitemark, but who does it and how will show where power, authority and "wisdom" lie. It may increase the clash (I have chosen that word to describe the interaction) between the orthodox scientific world views/culture of the clinician and the wide range of alternative approaches/perspectives about life, meaning health and healing, well being etc that exist around the world. Today (Thursday) there is a call from cancer charities for kitemarking of cancer sites. It will be interesting to see if it happens, who makes the decisions and how they are made!*

Only two comments were made about quality control, one advocating kite-marking of websites. Expertise of searching skills and use of facilities such as chat rooms and discussion fora was also predicted to increase. Three respondents felt that patients would take a more active role in their own health care management, particularly in relation to shared decision making. There were also comments (n=4) about the digital divide, which although most felt would decrease in the future, one person felt that the divide would continue to increase.

> *I believe as technology becomes more accessible to all and the information divide decreases patients will continue to be empowered to take a more active role in their healthcare management.*

6.5 Summary of main findings *(Study objective 5)*

A number of key themes arose from the discussion forum. Quality issues were deemed important, but were considered to be only one of many areas of interest in the use of health internet information. Exchanging patient experiences through online resources were described as an increasingly popular and valuable resource for patients. The 'informed patient' was viewed in a positive way, yet difficulties were highlighted about discussing internet information in consultations. Comments were also made about the impact that information can have for the patient, such as an increase in autonomy for their decision making. Self-care of existing conditions was supported, yet attempts at self-diagnosis were not given approval. Lastly, training and education was described as necessary to assist patients and health professionals when using health information from the internet.

An evaluation of the discussion forum resulted in a positive response to using an online forum for exchanging ideas. Use of the forum was low, mainly due to lack of time or the participants did not feel compelled to respond to the forum topics. Survey respondents predicted an increase in future use of the internet and greater involvement of patients in managing their health care.

In conclusion, the findings that were obtained from the discussion forum support many of the comments highlighted in Phases 1 and 2 of this study. These findings have highlighted that patients, health professionals and academics have many shared views about the use of the internet as a source of information for patients.

CHAPTER SEVEN

DISCUSSION

7.1 Introduction

'The patient will see you now doctor'

(BUPA Advert, 2004)

Patients' use of the internet has received considerable attention by the public, media and academics. Much of this attention has criticised the internet, with warnings that patients may be at risk of accessing unregulated information or utilising poor quality information (Kunst *et al.*, 2002). Given that there has been such a focus on these issues, it is surprising that there is little empirical data on consumer experiences of using the internet for health information. There are also assumptions about the potential influence of the internet on the doctor-patient relationship, yet this is founded primarily on theoretical discussions by academics or the perspectives of health professionals. This thesis therefore, aims to add empirical data to this debate by exploring patient use of the internet and its impact on the concept of patient-centredness. This study had five main objectives: the ways in which patients use health information; the impact of socio-economic status; the role of the internet as an information source; patient and professional views about internet information in primary care consultations; and national and international perspectives on the use of the internet in primary care.

The study objectives were addressed in three distinct phases. The previous chapters (four to six) presented the empirical data from each phase of the study. In Phase 1 a survey was used to explore the extent to which patients used information sources and their use (and non-use) of the internet for health information. The survey provided a quantitative description of current information seeking and informed a more exploratory approach in Phase 2. Perspectives gained during the interviews in the second phase provided a detailed insight into the ways in which the internet is used in primary care. It must be noted that these views were not all based on direct experiences, as some were focused on perceptions about potential applications of health information. The interviews served as a means of understanding why and how patients chose to use information in the context of their own health. Phase 3 offered national/international perspectives about use of the internet in primary care,

so that the findings could be placed within a global context and not just confined to the views of patients and professionals in South Wales.

This chapter synthesises these findings and offers comparisons to existing literature in this field. The extent to which the study has answered the research questions posed at the beginning of the thesis can then be evaluated (p 11). An interpretation of these findings is presented within a theoretical framework of patient-centred care.

7.2 Patients' acquisition and use of health information

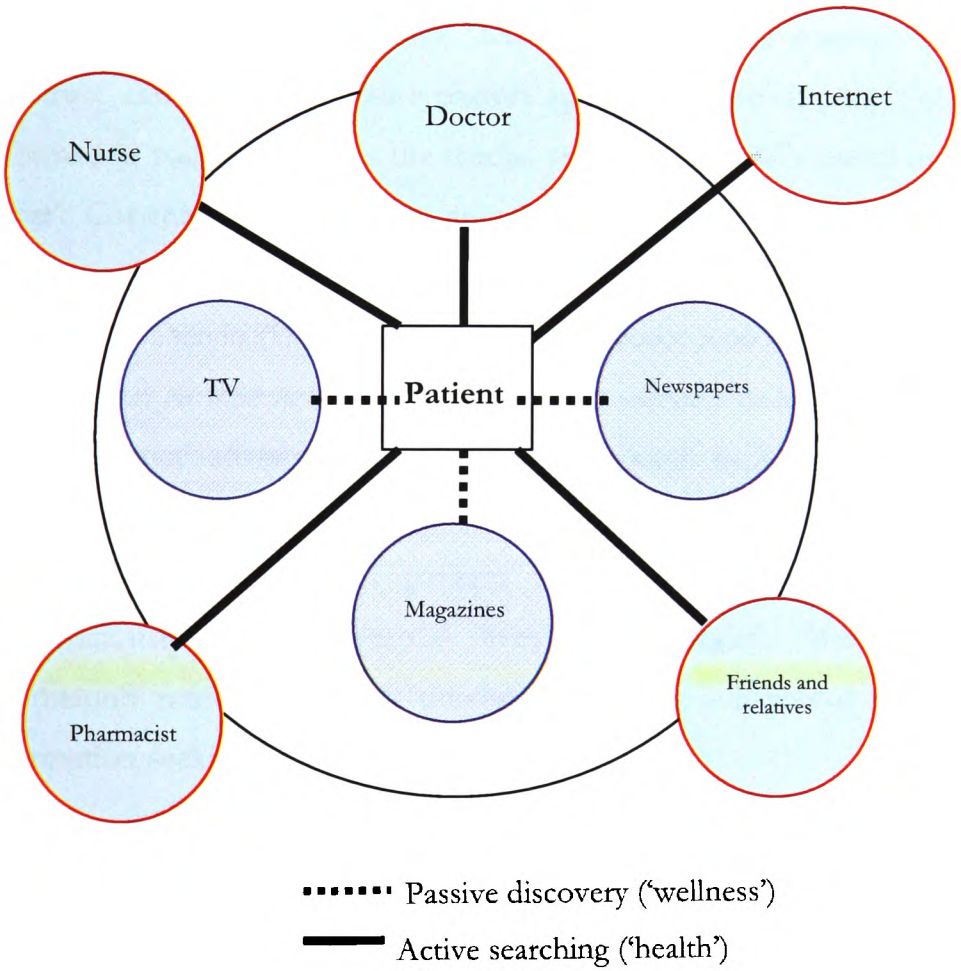
Conveying information effectively to patients is an important feature of modern health care, as is the shift towards involving patients more in decisions about their own healthcare. This information is typically provided by health professionals; however more recently many patients are accessing a variety of other information sources. A reflexive interpretation suggests that patients constantly strive for self-improvement which can be achieved by seeking and evaluating new knowledge (Giddens, 1991: 40). Overall, patients in this study supported this notion of acquiring knowledge as they preferred to be well informed about their well-being.

Patients in this study used a variety of information sources for health, yet the majority relied on health professionals, primarily their doctor, pharmacist or nurse. A high proportion of patients (80%) had accessed their doctor for information about an illness during the previous six months. This compares well with existing literature, suggesting that patients prefer to access health professionals to meet their main information needs (Cohall *et al.,* 2003; Sparado, 2003). Patients demonstrated a pro-active approach to information seeking, which was justified as an expressed need for information pertaining to a health problem. This behaviour is consistent with reports on the information seeking of specific patient groups (Raupauch *et al.*, 2002; Fox and Kilvert, 2003). However, this category of information is primarily associated with illness and disease, signifying that it is not harnessed as a form of promoting health. Following the Wanless Report (2002), recent health care policy in the UK places an even greater emphasis on preventive medicine. It is recognised that accessing health information alone does not necessarily lead to behaviour

change; however it can play an important role in the use of health services (Grilli *et al.*, 2002).

Figure 7.1 outlines the boundaries of health information seeking behaviour by patients in this study. It distinguishes between accessing general health information sources in an *ad hoc* way (predominantly media) and actively seeking information about specific health issues (health professionals).

Figure 7.1: Patient approaches to information seeking



It can be seen that passive discovery (wellness) is within the boundaries of patients' everyday experiences, whereas, actively seeking out information (expressed need) is not an everyday occurrence. For primary care patients, health professionals are only slightly outside the boundary as they are commonly used for information about

specific and more general health issues. Friends and family are also on the outskirts of the boundary, reflecting the observation that some patients rely on informal support networks to discuss their health concerns. The internet is widely used for information; however, it is currently beyond patients' everyday experiences as it is accessed more to address specific health needs.

Much of the literature on information seeking behaviour emphasises the concept of 'need' (Wilson, 1981). This concept relates well to active information seeking, whereas in contrast, a passive means of accessing information is not necessarily determined by a specific need. In early work on the use of information, Dervin (1983) makes the distinction between information as an 'observer construct' and information as a 'user construct'. The more traditional concept of the 'observer construct' can be aligned with a passive approach in which people rely on informal information sources, such as the media, and friends/family based on a 'law of least effort'. Conversely, information as a 'user construct' requires *'information for sense making';* or put more simply, people seek information that is relevant to their needs at that time. Dervin (1983) suggests that *'information needs are always personalised, as there is no other way for them to be'.* This viewpoint is relevant to health information, yet the 'user construct' advocates a medicalised approach to health information seeking. Active information seeking about an illness was most common for patients in this study (medical model), yet patients also accessed general health information subconsciously in their everyday lives (social model). Although this blend of information retrieval was not universal, it offers a balanced approach to health information seeking.

7.3 Socio-economic status and the use of health information

This study investigated use of the internet in two different areas of South Wales to examine whether there were inequalities in the use of health information. Socio-economic status was broadly determined according to the level of deprivation in the location of each practice. In addition, the variables of education, employment, age and gender were analysed on an individual level. The findings from the survey

strongly confirmed that patients from each practice differed significantly in socio-economic status.

Overall, the use of sources for information about illnesses was similar in each practice. The only significant difference was in use of the internet, which can be explained by inequalities in internet access. A different picture was presented for the use of general health information. With the exception of their doctor, patients from the more affluent area used nearly all information sources far more than those from the deprived area, which demonstrates a greater dependence on health professionals of patients with a lower socio-economic status. One concern is that more deprived areas are less well served by quality health care services and so patient information needs are less likely to be met. Patients may therefore continue to be victims of the 'inverse care law' in which Hart (1971) proposed that, '*....the availability of good medical care tends to vary inversely with the need of the population served*' (p 412). It could be suggested that patients of a higher socio-economic status had more of an interest in their health, or that they encounter more sources in their daily lives that are health oriented. Interestingly, this study's findings suggest the latter as the value that patients placed on their health was high in both practices with a mean Health Value score of 22 out of a possible score of 28. Health value however, was only measured by one scale (Lau *et al.*, 1986) and so further investigation would be needed to substantiate this finding.

The findings also revealed some gender differences in the use of health information. In general, women used information sources more frequently than men. The most notable difference was displayed in the use of magazines with significantly more women (49%) than men (29%) using magazines for general health information. These findings suggest that men and women acquire health information in different ways. Women generally report higher levels of illness and use of services than men (Wyke *et al.*, 1998; Clarke, 2001; Saltonstall, 1993). It is also widely acknowledged that men have a much lower interest in health issues than women. Evidence for this health divide is socially constructed by gender boundaries in which men advocate masculine beliefs often resulting in unhealthy or risky behaviours (Courtenay, 2000). This divide is supported by the limited access of health information by men in this

study. It is important that men's health issues are targeted as a high priority by considering ways in which men can be encouraged to access information. In contrast, there was little difference in use of the internet for health by gender of the total sample (males = 50%, females = 54%). General use of the internet is greater in the male population (e-MORI, 2002). The internet could therefore be a valuable way of targeting information to men about their health in the future.

At the time of this survey, 57% of UK population had accessed the internet at some time and 40% had access to the internet at home (ONS, 2001b). The figures in this study are similar as half (51%) of all patients had access to the internet and 43% of all patients had access at home. Such comparisons should however be treated with caution as the concept of access can be open to interpretation. A person may have access to an internet connection in their home, yet it may be used by other family members. In the current study patients stated whether they had internet access, however they were also asked about use of the internet which confirmed that they were internet users (see page 34 for further discussion).

Technological developments continue to prevail in all aspects of society. Although such developments can be advantageous, by providing greater efficiency and expertise, they can also enhance inequalities in society. Significantly more patients from the affluent area (62%) had access to the internet than those in the more deprived area (28%). The digital divide was even greater between young/middle aged patients and the elderly. Only 16% of all internet users were aged 55 and above. Given that this age group accounts for a third (30%) of this sample and an even greater proportion (37%) of the general population (ONS, 2000a), internet use is very low amongst this sector of society. This study highlights the current problem of a digital divide in relation to age and socio-economic status, which needs to be addressed.

Figure 7.2 categorises the socio-economic characteristics that effect use of the internet for health. The impact of deprivation on internet access is mediated via age, gender and occupation/education parameters. Patients from Practice 2 had lower access and lower employment. Consequently, older male patients from deprived

areas are the least likely to access the internet for health information. In contrast, younger women from more affluent areas are most likely to make use of the internet to manage their health.

Figure 7.2: Inequalities in use of the internet for health information

Effect	Determinants of internet access
HIGH	Age (less access in >65 years)
HIGH	Occupation/education (less access in social class groups 5 {*skilled trade*} and 9 {*elementary occupations*}).
MODERATE	Gender (less access by males)

An encouraging finding of the study was that patients who had access to the internet used it in fairly similar ways regardless of the practice they attended. There were however differences in understanding and trust of internet information. The majority of internet users interviewed from Practice 1 (90%) talked about the process of understanding internet information, whereas only half of patients from Practice 2 discussed these issues. Interestingly, patients from Practice 2 were more concerned about the trustworthiness of the information than those from Practice 1. Patients from Practice 2 were generally less experienced users, which may account for these discrepancies. This finding reinforces the need to provide training and support for patients using the internet, particularly in relation to interpretation, analysis and critical reflection on the information obtained.

The health applications accessed via the internet are becoming more diverse. An increasing number of health-related services are now available electronically, for example, booking appointments online (Department of Health, 2005a), yet few patients referred to these wider applications in this study. As technology develops in the delivery of health care, some patients may be further disadvantaged due to their

inability to access new dimensions of health care services. There is therefore a greater need to raise awareness about public access to information sources such as the internet, whilst acknowledging that some people may not be happy to access personal health information in a public place. Patients preferred to search for health information in the comfort of their home where they had more time to process and understand information. This is supported by a recent survey (Vermass and Wijngaert, 2004) which found that internet users (n=123) were more likely to access online patient fora if they had an internet connection at home. Comments from the discussion forum in the current study focussed on the belief that the digital divide would narrow as costs of the technology decreased. Costs are decreasing, but the results of this study suggest that cost is not the greatest constraint on access to the internet; other considerations include lack of interest or time. Only 12% of patients in the interviews did not have access due to cost, which supports findings from a survey in Wales stating that only 1 in 8 (12.5%) were deterred by cost (Welsh Consumer Council, 2003).

There was a perception by non-users that the internet had great potential. Some felt they were missing out on a valuable resource, whereas others had neither the interest nor time for the internet. A quarter of patients in the interviews (27%) described indirect access to the internet through friends and family. This suggests that an even greater proportion of the population may access the internet for health information. Current estimates about internet access are therefore likely to be conservative, as they report predominantly on direct access. Indirect access further reinforces the ambiguity of the concept of access as people without direct access can also make use of internet information.

7.4 The role of the internet as an information source

Health information is reported from global surveys as the one of the most common search topics for internet users (Datamonitor, 2002). The current study confirmed the popularity of the internet, with half of users accessing health information, and most (75%) during the previous six months. Use of the internet was comparable with other media such as newspapers, TV and books. UK estimates prior to this

study ranged from as low as a third to 57% of people using the internet for health (Eurobarometer, 2000, Datamonitor, 2002). It is acknowledged that patients in this study were selected from a general practice population and so were more likely to be interested in health issues than the wider population.

The internet has been described as an *'encyclopaedic health resource'* which can educate and empower the user (Powell *et al.*, 2003). The internet does indeed offer these potential benefits, although capitalising on these is dependent on the patients' ability to retrieve and appraise relevant information. The internet has potential to offer a valuable source of information for people with disabilities, yet there are numerous barriers to effective use, such as complex site design, multi-tasking demands, and the format/style of websites (Parr *et al.,* 2003). Patients in this study did not refer to particular disabilities, yet some expressed their concerns about the complexities of searching on the internet. The interviews provided an opportunity for patients to describe their searching strategies on the internet. Search engines were most commonly used, despite the volume of information they produced. Named web-sites were preferred to search engines, yet patients could generally not recall specific websites or describe how they appraised the information contained therein. This supports earlier findings from a small observational study which found that, although consumers were successful in findings answers to health questions, they did not recall the websites or the source of the information (Eysenbach and Kohler, 2002). Patients who are given appropriate training can benefit from using web-based tools to promote health gains (White et al., 2002). Evidence of inefficient searching techniques illustrates that the public could benefit from guidance and/or training in using the internet.

Patients in the current study were more confident in accessing websites that were recommended by others, particularly by health professionals. Health professionals described situations when they referred patients to websites, for example, to help patients with mental health problems. It was however interesting to note that none of the patients described experiences of such referrals Although the sample of patients interviewed was relatively small, it would be expected that at least some patients would have experienced this in practice, if web referrals were common. A

recent small-scale found that with only 7% (n=8) of patients reported referrals to websites from their physician (Vermass and Wijngaert, 2004). GPs in the current study acknowledged that referring patients to websites was not routine; other primary care staff were more reluctant to do this due to their lack of awareness of validated/reputable websites. Recent health care policy supports the need for an 'information prescription' issued to patients by health professionals (Department of Health, 2004a). However, there are concerns about the difficulties posed for patients who may not have access to or the ability to use the internet (Childs, 2005). One way to overcome such difficulties is the use of touch-screen kiosks which were developed in the early 1990s (Jones *et al.,* 1993). InTouch with Health kiosks are now widely available in primary and secondary care and offer a suitable way of providing information that can be accessed in public areas (Boudioni, 2003). Such initiatives are likely to be welcomed by patients given the preferences in the current study for internet information that was recommended by their doctor.

Staff and patients reported an average proficiency in using the internet (6 months to two years experience), the majority of whom were self-taught. There was little evidence of the experienced 'power users' described by Fox (2005). Searching on the internet was an intuitive process for patients and staff based on an estimation of the most effective strategy. Both staff and patients found it difficult to express a rationale for selecting information and so are likely to benefit from training in this area. It may be that users were cautious about assessing their own proficiency as they did not want to appear over confident. Health professionals in particular need to be trained in using the internet if they are to take on the responsibility of guiding patients effectively.

The internet is unregulated, although there are a number of useful tools which can assist users to appraise information.[1] The current emphasis on evidence-based practice suggests that health professionals should become experienced at critiquing evidence. In reality, it is likely that some health professionals will need training to develop or fine tune these research based skills. A number of government initiatives are available to promote ICT literacy, for example Learn Direct, yet uptake of these

[1] JUDGE http://www.judeghealth.org.uk and Hi Quality http://www.omni.ac.uk

services is fairly low. The health service has made some substantial ICT developments, yet these need a relevant infrastructure and support from ICT literacy programmes. ICT training schemes have been introduced, such as the ECDL, a recognised computer qualification throughout Europe. The ECDL focuses on seven areas of IT, yet has only recently included internet searching. Prior to this, the ECDL focused more broadly on information networks and so did not equip the user with the skills to search the internet. The ECDL has been welcomed by health service staff, yet it has focused predominantly on a small proportion of secondary health care staff, including medical students and consultants (www.ecdl-nhs.uk). It is hoped that further emphasis will be placed on ICT training in primary care following the revised curriculum (draft) proposed by the Royal College of Practitioners (RCGP, 2005a). The curriculum includes learning outcomes about Information Management and Technology (IM&T), with a requirement that all GP registrars achieve the ECDL standard by end of training. However, in line with much of the policy focus on ICT, many of the objectives focus on the use of electronic information systems for transferring information. It is also important to ensure that well established GPs receive appropriate ICT training.

Quality issues have tended to dominate the literature about health information on the internet to date. The over-emphasis on quality issues was echoed by participants from the discussion forum who called for research into new dimensions of the internet, rather than persistence with quality concerns that are not unique to the internet. It is argued that criticisms about the internet as a form of health information and associated calls for regulation may be attempts by the medical profession to monitor the internet (Nettleton and Burrows, 2003). In general, patients viewed the internet as increasingly important for the delivery of future health care and a powerful medium of communication. However, patients did not always question internet information rigorously. The duality of the internet was acknowledged by participants, in terms of finding a balance between trustworthiness and value. This tension highlights the contradictions inherent in this rapidly developing arena. Many of the respondents in the interviews talked about the potential use of the internet, rather than their personal experience of using it, for example for self-diagnosis, or discussions during consultations. Some patients who

had internet access still appeared to be reluctant to use it for health even though they would use it in other areas, such as online shopping or banking. It may be that for these patients health was not viewed as a commodity and so they chose not to take on the role of health consumer.

7.5 National and international perspectives on the use of the internet in primary care

The discussion forum in Phase 3 aimed to gain a broader perspective from national and international stakeholders in the field of consumer e-health[2]. The issues raised in the discussion forum support many of the comments highlighted in Phases 1 and 2 of this study. It is evident that national/international stakeholders share the views illustrated by patients and professionals in South Wales. Overall, use of the forum was low; however the forum provided some interesting perspectives on use of the internet in primary care. The methodological issues encountered during the discussion forum are examined in the concluding chapter (p 217-20).

Many of the postings on the forum confirmed existing evidence in the literature, such as the widespread use of the internet for health information (Fox & Rainie, 2000). Additionally, participants felt that there was an overemphasis on quality issues, which although important were no longer considered to be the central focus of research into consumer e-health (p 199). This thesis supports the contention that quality issues are an ongoing concern, yet should not dominate research in this area.

Perspectives gained in Phase 3 also supported the view that patients' use of information during primary care consultations is a contentious issue (Hardey, 1999; Diaz *et al.*, 2002). There was however a belief that patients are very resourceful in their application of the internet, for example self-care, which is often underestimated. The interactive nature of the internet, such as online discussion fora, was given greater emphasis than earlier phases of the research and the existing

[2] Where appropriate, additional issues from the discussion forum are integrated into other sections of this chapter.

literature (p 205). This is clearly an area of health internet use that is likely to gain increasing popularity with patients.

7.6 The internet and patient-centredness in primary care

This chapter has illustrated the complexities of patients' use of health information, including the internet in primary care. This section examines the views of patients and health professionals on use of the internet in primary care consultations within a theoretical framework of patient-centredness (objective 4). There has been a considerable policy drive towards patient-centred care in the UK. Conversely, the potential limitations of the internet have been highlighted due to concerns about the quality of information and the potential challenge that internet-informed patients pose to doctor-patient interactions (Ferguson, 2002). It is therefore considered appropriate to consider the role of internet-informed patients in relation to patient-centredness in primary care. This thesis did not intend to measure patient-centredness, yet offers an insight into how patients' use and non-use of the internet relates to the overall concept of patient-centredness. Mead and Bower (2000) propose five dimensions of patient-centredness; the biopsychosocial perspective; 'patient as person'; shared responsibility and power; therapeutic alliance and 'doctor as person' (p 54). The following sections discuss the main findings of this study using the framework offered by Mead and Bower (2000).

7.6.1 The biopsychosocial perspective

Firstly, Mead and Bower (2000) focus on the *biopsychosocial perspective*, primarily the '*Broadening of the explanatory perspective on illness to include social and psychological factors* (p1088). One preference of patients in this study was validation of internet information by a health professional. However, this preference is often difficult to achieve, particularly if the information focuses on more general health issues. Clearly, it is more acceptable for a sick 'patient' to discuss information with a GP than a 'well' consumer. The biopsychosocial perspective acknowledges all aspects of patients' experiences, including more general issues such as health promotion

(Stewart *et al.*, 2003). Evidently, for some patients in the current study, the broader health information needs of consumers were not being sufficiently addressed. This is not to say that health professionals do not advocate biopsychosocial perspectives. Although, not a major focus of the interviews, some patients felt that their GPs generally offered an holistic approach to their health care. One patient stated, *...doctors are not so quick to condemn... they are aware of a more holistic approach to medicine and that you are looking at a number of things'.* Broader elements of the biopsychosocial perspective are addressed in the subsequent dimensions of patient-centredness.

7.6.2 The 'patient as person'

The second dimension of patient-centredness, *'the patient as person'* has a particular resonance within this study. The personal meaning of illness for each individual patient is a well established component of primary care (Wonca Europe, 2002). There is an increasing amount of evidence suggesting that the use of personalised information provides high patient satisfaction in terms of usefulness and relevance of information (Jones, 1999; Coulter, 2002). A more recent randomised trial of cancer patients (n=325) revealed that patients were more likely to share personalised information with others; however, additional research is needed to investigate the impact of this information in terms of social support and levels of anxiety (Jones, 2006).

The consequences of using non-personalised or poor quality health information were acknowledged by participants at each stage of the empirical research. An encouraging finding was that patients mainly engaged in controlled use of information as they used a variety of sources and compared them against each other to clarify the answer to their question. One of the most common sources for this type of clarification was their GP. Health professionals were particularly concerned about patients' understanding of information from the internet as they may be misinformed, or find it difficult to make sense of the information. The findings from this study therefore support the growing demands for patient-tailored information, a complex process outlined on page 205.

A common criticism of internet information was that it often provided conflicting or confusing information. Yet this complaint is not unique to the internet. Nettleton (2004) contends that:

> The pros and cons of e-health are not the main concern here; the point is that health and medical knowledge are being metamorphosed into information and it is circulating beyond the walls of medical schools, hospitals and laboratories. Medical knowledge has escaped metaphorically and literally; it can be accessed and indeed is now increasingly produced by health consumers and users (p 673).

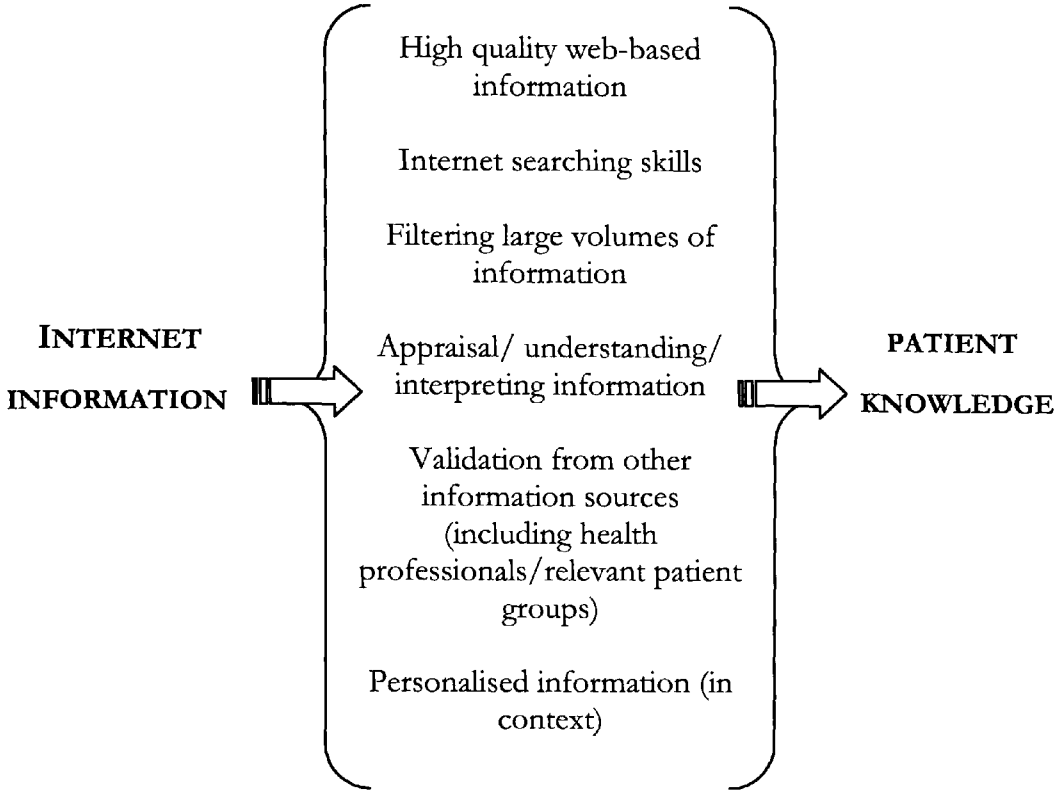
Given the difficulties that patients have when appraising information, they may not make the transition of transforming the information they have accessed into meaningful knowledge and health benefits. Despite 'misinformation' (Lash, 2002), the public are fully aware of the fallacies of medicine. It is often difficult to get a definite diagnosis, treatments can be controversial and there may be differences in medical opinions. In general, patients preferred information that was patient-centred, which contained less jargon, and promoted greater understanding. Such sentiments are interesting, given that in the past health information was criticised for its paternalistic attitude (Coulter, 1998). The challenge of providing well balanced information that is easy to understand, but detailed enough for patients, has yet to be realised.

The huge volume of information encountered by patients when searching about health issues further reinforces the need to encourage users to develop their IT skills, in order to filter out the health information that is relevant to their needs at that point in time. One way of managing the difficulties of searching is to personalise information with health records. Personalised information is often associated with major cost implications, particularly in primary care due to existing pressures on this service. However, current developments in computer-based patient information have the potential to provide personalised information for patients at the same cost as general health information (Jones *et al.,* 1999). An additional way in which to increase the amount of user-friendly information is to have more patient involvement when developing health information materials.

Patient-tailored web-based tools such as the BackInfo project have developed as a result of patient requests for information that takes account of an individual's life situation (Glenton, 2002). Personalised health information should facilitate holistic approaches, inherent in patient-centred care, as it incorporates all aspects of the patients' health record.

Evidently, accessing health information from the internet is a complex process for participants. Figure 7.3 outlines the processes involved in turning internet information into meaningful patient knowledge. In 2003, the Department of Health highlighted the importance of patients having the right information suited to their personal needs. This study demonstrates that despite the claims by health care policy makers (Department of Health, 1998a), accredited internet information is not being provided. The lack of accreditation may be due to a number of factors. First of all, a higher priority has been given to ICT infrastructure and the use of ICT by health professionals. This support is a positive step for future developments of their role as facilitators of patient information, yet further attention should be given to the patient. Secondly, the aims of policy directives about patient-centred care are widely supported by consumers and health professionals, yet little consideration has been given to achieving these aims. It is encouraging to note that the RCGP have recently focused on the application of IM&T to person-centred care, which proposes that a GP should be able to, '*use the availability of computerised resources to tailor information to the needs of patients* (RCGP, 2005b: 7). Elements of an holistic approach are cited as core values of general practice; however, the application of IM&T in this area is vague, merely suggesting that GPs have an understanding of how IM&T contributes to patient-centredness.

Figure 7.3: Steps in transforming internet information into patient knowledge



7.6.3 Sharing power and responsibility

The notion of sharing medical power is now widely established in the literature (Bauman *et al.*, 2003). User involvement, shared decision making and evidence-based patient choice are well established therapeutic strategies (Edwards and Elwyn, 2001). Patients have the right to be appropriately informed about their health. Information plays an important role in patient's autonomy of their health care. It is widely acknowledged that an important aspect of generating respect for patients is to have respect for their autonomy (Sullivan, 2003). Coulter (2002) argues that in order for clinicians to respect patient autonomy they must *'... acknowledge their (patient's) right to hold views, make choices and to take actions based on personal values and beliefs'* (p8). It has been illustrated that patient information can be obtained in a variety of ways, and its use can encourage patients to take more control of their health. The informed patient therefore confirms early beliefs that medical dominance is engendered by ownership and control of knowledge and its production (Freidson, 1970). Decision making is therefore no longer solely in the hands of the health professional, but may

be led by the patient (Davis *et al.*, 2003). Patients are no longer passive recipients of care, but are *'negotiators of a problem, able to make choices about its management, express subjective experiences and wants, and to adjudicate on the quality of care they receive'* (May *et al.*, 2004).

An autonomous patient may not always feel a need to access their health professional and may engage in self-help. Self-help is an effective strategy for managing certain health problems; for example, self-help materials such as bibliotherapy[3] are used by people with mental health problems who can experience significant benefits from their use (Lewis *et al.*, 2003). Many minor health problems are dealt with through self-care/management. Rogers *et al* (1998) claim that even a small decrease in self care would have a significant impact on the demand for health services. Online discussion fora on the internet offer informal support networks which can promote greater patient involvement in the form of self-help. This type of internet use was not widespread in this study. However, the increasing availability of such fora was valued by patients and practice staff. Members of the discussion forum felt that online patient chat rooms would be used far more extensively by patients in the future. Their own experiences with patients showed that gaining awareness of an illness by exchanging ideas with other patients was used to validate decision making. This view was also supported by health professionals who had accessed them to gain further insight into *'the patient experience'*. These resources are valued as they are based on real experiences, rather than the views of the doctor. Computer mediated communication offers patients a means of accessing information confidentially and provides discreet interaction that may be more appealing than face-to-face discussions (Macintyre, 2003). Chat rooms provide a way for patients to share experiences, but can also give authority to patients who control the discussions. This information can be criticised due to the lack of objectivity, yet the subjectivity of the information is often the main attraction for patients. On a macro-level, the impact of patient groups may lead to more sustained consumer pressure on health issues. Acknowledging these issues will be crucial for policy makers too as they have to develop in tandem with an accredited approach for the internet to really flourish in the future.

[3] Bibliotherapy - delivering psychological treatment using self-help books.

Patients in this study also demonstrated increasing responsibility in managing their health by engaging in self-diagnosis using information from the internet. Self-diagnosis was a popular issue in the interviews for internet users and non-users. Patients in this study were mindful and cautious of the implications of self-diagnosis. The amount of internet use for self-diagnosis (20%) was consistent with previous research (Williams *et al.*, 2002). However, nearly all patients in the current study sought subsequent advice from their GP. Whereas, in more recent work, Williams *et al.* (2003) found that half of patients conducted a self-diagnosis to avoid consulting their GP. Evidence of a cautious approach is encouraging given the concerns about the quality of information on the internet. Such caution however does not rule out people who may not seek medical advice following an initial self-diagnosis. Patients in this study were active attendees at general practice and so were more likely to seek advice from health professionals. Non-users of health services could be at an increased risk if they choose solely to rely on the internet to self diagnose their health problems. These concerns are widely documented in the literature, however, evidence suggesting that the internet causes harm is inconclusive (Bessell, 2002). A lack of clarity should not lead to complacency as some of the ill-effects of the internet may as yet be undiscovered. It is likely that such ill effects may occur, yet they are under-reported in the literature.

On the surface, health professionals and patients in this study appear to be shifting from the medical model of care. However, the reluctance of patients to introduce information for discussion in consultations clearly demonstrates that current practice reinforces traditional doctor-patient interactions. This approach was particularly apparent for patients of a lower socio-economic status, who relied more on their doctor than any other information source. However, those actively seeking additional information sources often leave the interpretation of information exclusively to their doctor. It may be that some patients are not ready to follow proposed models of independent choice (Quill and Brody, 1996). Some patients want increasing autonomy for their health, yet they are reluctant to demonstrate this in practice as they do not wish to upset the traditional doctor-patient relationship.

Other patients in this study clearly strived for a balance between autonomy and gaining the necessary support from health professionals. Evidently, they are still wary of adopting an autonomous role. It is important that the increasing focus on patient autonomy does not result in situations where *'...clinicians unwittingly impose autonomy on patients'* (Borell-Carrio *et al.*, 2004). Although policy trends advocate patients taking a lead role in their health care, many patients still wish to rely on their GP when digesting health information, and continuing to facilitate this choice is important. Reflections posted by a GP on the discussion forum indicated the potential for patients to become more involved in their decision making by accessing internet information (pg 180). Interestingly, this GP described the exchanges as a 'game', the first of which was won by the 'patient' and the second by the GP. A subsequent posting offered clear support for more informed patients with a view that, *'The internet has given him more information and therefore power behind his questions'*. This GP was clearly challenged, but felt that the patient was making a reasonable argument based on reputable evidence. Such exchanges are more difficult with internet evidence that lacks quality or relevance. The modern patient may therefore place added pressure on the already constrained GP consultation. Experiences of patients and primary care staff in this study showed that some aspects of primary care do not appear to be able to cope with the information needs of the currently ever demanding patient. This is a peripheral aspect of primary care, but the demand is likely to increase. The positive attitude from health professionals in this study suggests that they want to better understand the patient experience. The next challenge is to consider ways of harnessing this support in practice within the context of financial, organisational and political constraints.

7.6.4 The therapeutic alliance

A foundation of patient-centredness is the personal relationship between the doctor and patient. Mead and Bower (2000) emphasise that the therapeutic value of the doctor-patient relationship must be a core feature of medical treatment, rather than a *'potentially beneficial side-effect'*. Chew-Graham *et al* (2004) contest the importance of the doctor-patient relationship, describing 'harmful consequences' of focusing on this relationship as the main goal of consultations. However, the impact of the more

informed patient on the doctor-patient relationship is an area which is receiving increasing attention. Much of the literature adopts a critical viewpoint suggesting that challenges to the paternalistic approach are not welcomed by health professionals (Hogg *et al.*, 2003; Murray *et al.*, 2003). A quarter of patients in the current survey (24%) had used information sources during consultations, and nearly all patients in the interviews described experiences of discussing information accessed from the internet, or other sources, during a subsequent consultation. There was however a reluctance to present printed internet information to a health professional during a consultation.

It has been argued that the internet is merely another form of information that is not radically different from other information sources (Sheppard and Charnock, 2002). However, the internet has produced an explosion of health information through which patients can now access a vast array of specialist material. Patients and practice staff in this study demonstrated that using the internet can be a more complex process than when using more traditional information sources. The combination of having a disorder and gaining health knowledge about it can be quite powerful for patients who have the ability to use the internet. Patients may therefore develop a greater (lay) medical competence in comparison to their GP (Lupton, 1994).

This author contends that the warnings about a surge of internet informed patients approaching their GPs are currently unfounded. This is a logical conclusion, given the low number of patients (1.26–2.27 patients per month) presenting internet information to health professionals (Malone *et al.*, 2004). The current study has provided a new dimension to this debate as it is evident that many patients would like to present information to their GP for discussion during consultations, yet they are reluctant to do so. Some patients may prefer their relationship to be more of a 'meeting between experts' (Tuckett *et al.*, 1985), yet some 20 years on from when Tuckett introduced this notion, it has been difficult to achieve. Previous studies have focused on the views of health professionals who predicted difficulties or changes to consultations with internet informed patients (Nwosu and Cox, 2000; Murray *et al.*, 2003). Patients and health professionals in the current study described

positive and negative experiences of discussing internet information. Three quarters of survey respondents who had used the internet during consultations felt more prepared and able to participate in decision making. However, only a third felt that their health professional listened more to them as a result. The Internet Users Survey demonstrated similar outcomes; 70% of internet users felt more empowered as they had the ability to ask their doctor informed questions (USDC, 2002). Clearly, it is possible to facilitate use of information in consultations to the benefit of the therapeutic alliance.

Salmon and Hall (2003) suggest that patient-centredness is more appropriate for consultations focussing on diagnosed diseases and is less successful for unexplained conditions. This view is echoed in the work of Malone *et al.*, (2004) who found that GPs were more positive about discussing internet information post-diagnosis. The challenge here is therefore not the internet *per se*, but the introduction of new knowledge with which the doctor may be unfamiliar. It may be that GPs do not wish to spend time on non-existent (undiagnosed) illnesses, or that they are merely sceptical of internet information. Patients in this study predominantly searched the internet regarding existing conditions, yet still felt uncomfortable about discussing this information during consultations. Patients hesitant to present information to their health professional may instead attempt their own interpretation of the information during a consultation. Patient interpretations pose problems as the health professional does not have the opportunity to view the information directly, which may result in confusion. This situation could in turn increase consultation time and result in frustration for both the patient and health professional if some issues remain unresolved.

Patients frequently used internet information as a form of 'health supplement' as they were not seeking an alternative to their health professional. Yet others may feel forced into seeking refuge in the internet as an alternative source of health information due to frustrations with care provision. A third of patients (30%) felt it was inappropriate to introduce information to a health professional, regardless of the circumstances. This was not to say that they did not wish to discuss information, but their beliefs about the traditional therapeutic alliance prevented them from

introducing information. It is likely that such patients would find it difficult to shift the established boundaries of the doctor-patient relationship.

Potter and McKinlay (2005) argue that patients and physicians have the potential to enhance the doctor-patient relationship by continuing to educate patients to make best use of their time in consultations and providing further training for physicians in communicating with patients. However, they contend that organisational pressures and constraints are the greatest factors that warrant consideration in the doctor-patient relationship. Discussion forum participants also highlighted potential constraints in practice. Generally, they were positive about patients being more informed. They were however realistic about the practicalities of managing consultations with patients informed by the internet, suggesting that consultations may need to be extended to make sense of detailed information.

7.6.5 The 'doctor as person'

The final dimension of patient-centredness focuses on how the personal qualities and values of the doctor can influence their practice. Mead and Bower (2002b) claim that the 'doctor as person' is the least explored area of patient-centredness and warrants further investigation through more qualitative methods. Although qualitative data in this area are beginning to emerge (Tarrant *et al.*, 2003), the tools used to measure patient-centredness are predominantly quantitative (Little *et al.*, 2001; Stewart *et al.*, 2000). The personality of the doctor may serve to assist, or impede patient-centredness. A recent extensive survey of primary care patients (n = 116, 939) revealed that patients were positive about their experiences of primary care, feeling that they were treated with respect and that their doctor listened to them carefully (Healthcare Commission, 2005). There were however, criticisms about insufficient information, such as the side effects of newly prescribed medicines. Patients in the current study talked broadly about their experiences of consulting with different doctors. On the whole, patients were positive about the personal qualities of their doctor, with some reporting preferences for particular doctors based on their style of consulting or the strength of the patient-doctor bond.

An important consideration in relation to the internet is the doctor's perceptions about its value as a source of medical information. Doctors with a negative perception of the internet may be less responsive to internet-informed patients. Though as time goes on the number of health professionals with no internet experience will decrease. Those with personal experience of using the internet may be more amenable to internet-informed discussions. Concerns about the internet proficiency of health professionals have been explored earlier in this chapter (pp 197-98). A current limitation of internet use is that many health professionals are not confident in their own internet skills and so may not be in a position to recommend self-evaluated web-sites. It is necessary to educate patients about how to appraise evidence so that they too can become self-sufficient in their searches (Houston, 2002). Many of these issues could be more effectively managed with ICT training and an increased involvement by primary health care staff to assist patients to understand internet information.

7.7 The modern primary care patient

One important concern for patients appears to be how they are perceived as a patient, with nearly all referring to how their doctor would react to their health information seeking behaviour. A large majority still prefer to defer to their doctor, suggesting that many patients still adhere to some of the traditional notions of the patient. The findings from this study have enabled the researcher to construct some distinctive patient categories of information use. Table 7.1 depicts four patient categories that have been identified over the course of the study to capture the characteristics of patients' use of health information.

Table 7.1: Use of health information - primary care patient profiles

1. Information avoider – prefers not to be informed for fear of what they may find out. They are a minority group, only accessing their GP when really necessary.
2. Conservative patient – relies on their doctor (or other health professional) for necessary information about specific health concerns, but only seeks additional information when needed.
3. Knowledgeable partner - active information seeker who strives to be well informed about their own health and that of others. Can be self-sufficient, but ultimately relies on health professionals for information.
4. Quasi-professional – highly informed patient that shares knowledge with other patients and health professionals about specific illnesses commonly based on their own experiences of a particular illness. Works in partnership with health care providers based on a reciprocal relationship. Provides a useful source of knowledge for other patients and health professionals.

None of these patient groups seek complete independence from health professionals. In each of these cases, the health professional has a role in the patient's use of health information. The extent of this input depends on the relationship between the patient and GP. Patients who took part in the interviews were categorised by considering the approaches used to acquire information, the amount of information used and how they engaged with health professionals in primary care. Based on the criteria in Table 7.1, the majority of patients (54%, n=27) are categorised as knowledgeable partners and a slightly smaller proportion (44%, n=22) are conservative patients These categorisations suitably reflect the findings discussed so far in this chapter as the majority are active information seekers; however some patients demonstrate a greater reliance on their doctor. Only one patient clearly avoided information. stating that he would prefer not to know what was wrong with him *'so that he would be able to sleep at night'*. Although this patient had a heart condition the following extract illustrates that he did not wish to have information about his condition, or any other aspect of his health:

Interviewer:

Did they give you any information about that, did they give you any leaflets or anything?

PT45

Oh yes, I can't say I read them mind.

PT45

I don't access information. No, I don't want to get up in the morning and think what is wrong with me. If I can't do something, I don't want to know why, that's the way it is. I don't want to know, no medicals, nothing. That is just the way I am.

The analysis did not identify any quasi-professionals in this study. However, this type of patient is recognised and likely to become increasingly common, following initiatives such as the Expert Patient.

A profile of interviewed patients from each practice illustrates some noticeable differences between each practice (Table 7.2). Patients from Practice 2 were more conservative with health information, only accessing information when really needed. Patients from Practice 1 were much more resourceful and were keen to be well informed about a variety of aspects of their health. Men were also more conservative in their style of information seeking, particularly those from Practice 2. Such differences in the role that patients adopt could serve to further reinforce health inequalities. The practice divide supports the concerns of Bastian (2003) that, *'better equipped patients corner more and more of their doctor's time'*. The more knowledgeable patient may therefore have more valuable interactions with their doctor, even though their health information needs could be met through alternative sources. Paradoxically, those with greater dependency on their doctor may not capitalise on interactions with their doctor and continue to act in a passive manner.

Table 7.2: Patient health information profiles by practice

Patient type	Practice 1 % (n)	Practice 2 % (n)
1. Information avoider	-	6 (1)
2. Conservative patient	38 (13)	56 (9)
3. Knowledgeable partner	62 (21)	38 (6)
4. Quasi-professional	-	-
Total	100 (34)	100 (16)

This patient profile is largely based on the ways in which primary care patients accessed health information in this study. Those not accessing primary care services could be classified as information avoiders as they do not wish to be informed about their (ill) health. However, classification of these patients is difficult as they may be managing their own health care through self-care.

7.8 Conclusion

This chapter has discussed the findings of the study in the light of the available literature and provided a rationale for the ways in which patients use the internet and other sources of health information. The findings in this study were derived from two general practices in South Wales, offering a regional perspective on patients' use of health information, including the internet. Chapter Four highlighted that overall the sample was generally representative of the wider population. Internet access in this study is also comparable with the general population according to socio-economic status. These findings therefore offer wider generalisability to other general practices in Wales and the UK.

Health information on the internet can be a valuable resource for patients, yet the findings of this study suggest that the digital divide continues to prevail. The internet has the potential to facilitate patient-centredness, by assisting patients to become more involved in managing their health care. However, it also has the potential to challenge the therapeutic alliance as the patients may place increasing demands on health professionals. The following chapter offers some concluding remarks and makes recommendations for future developments in policy, practice and research arising from this study.

CHAPTER EIGHT

CONCLUSIONS AND RECOMMENDATIONS

8.1 Introduction

The aim of this study was to explore patients' use of health information from the internet in the context of primary care. More specifically, there were five objectives, by which this aim was to be achieved:

- Consider the ways in which patients use health information;
- Examine the impact of socio-economic status on the use of health information sources, including the internet;
- Investigate the role of the internet as an information source;
- Explore patient and professional views about internet information in primary care consultations;
- Provide national and international perspectives on the use of the internet in primary care.

This chapter begins with some reflections on the methodological challenges encountered during this study, before drawing conclusions from the research in relation to the study objectives. An illustration is then offered on the ways in which the current study contributes to knowledge about consumer e-health in primary care. The chapter concludes with recommendations for policy, practice and further research.

8.2 Methodological issues

Conducting social research offers an interesting and exciting means of study, yet it often brings with it some methodological concerns. As the study progressed, a number of shortfalls were identified in the research process. A more detailed appraisal of the discussion forum is included as this posed the greatest challenge.

Patients were selected from general practice due to the author's interest in the role of the internet in primary care. Chapter Four outlined that, with the exception of

gender, the sample was representative of the general population. This study did not however measure ethnicity as a socio-economic variable as this was not recognised as an influencing factor in information seeking in the locality under investigation. The gender bias towards women is representative of those attending general practice and so offers a genuine perspective. The gender imbalance was particularly apparent in the interview sample in Phase 2. Consequently, analyses were conducted using relative proportions. Given the gender inequalities in the use of health information, it is particularly important that a more balanced representation is achieved in future research.

Overall, the questionnaire provided an appropriate means of obtaining data about patients' use of health information. A pilot study was conducted to examine the reliability and validity of the questionnaire. Although a number of amendments were made to the questionnaire other redundant factors became apparent during the analysis. The list of health information sources provided in question 1 (n=16) may have been too prescriptive. During the interviews patients talked more broadly about sources such as the library rather than books, or their use of consumer groups rather than listing individual media of health information. However, patients were given an 'other' category so they did have the opportunity to state a source based on their own categorisation. On reflection, it could have been more appropriate to allow patients to list their own information sources.

The question on internet use (Q7) could have been reworded to make a clearer distinction between access and use (see comments on p 194). A person may have answered 'yes' to internet access (Q6), but may not have been an internet user. There were however only 7 missing values from 419 responses for the question about length of internet use (Q8) indicating that nearly all of those with internet access had made use of it. The phrasing of the last statement in question 11 of the questionnaire *'I trust my health care professional more than the internet'* (p 280) could have been open to interpretation if considered in isolation. However, the preceding statements were all focused on the consultation and so provided a context for this statement. It would have been appropriate to include a word to clarify the nature of this trust. It also became clear from the analysis that some of the questions were

redundant. Consequently, question 4 and 5 were not included in the analysis. As discussed in Chapter 4 (p 121), it would have been appropriate to investigate deprivation at the level of the individual patient using the WIMD. Future research should take into account that different deprivation levels could be found within the area covered by each practice.

The main focus of this study was the patient perspective. A small number of interviews were also conducted with health professionals from each practice; however, the practice staff and patient samples were not intended to be equal. It is recognised that the number of practitioners was limited and that their views are not generalisable to all those working in primary care population. Patients talked about their experiences with health professionals, so this does give an additional insight about professionals in primary care. Future studies may consider a more detailed comparison of the patient and professional perspective, particularly in relation to their joint perspective on internet-informed consultations.

The interviews were conducted using a semi-structured approach which is the most common style of interviewing. They produced some interesting and rich data on the experiences of patients and health professionals' use of health information. However, these issues could have been explored in more depth by adopting a less structured or narrative style of interviewing. This approach would however have led to a reduction in the sample size and would bias data from patients that were active information seekers/internet users who felt they had a story to tell. Patients were selected randomly from a convenience sample and so it would be have been difficult to select suitable patients for a more unstructured interview.

Phase 3 was the researcher's first experience of designing and running a discussion forum and was a novel implementation in this research field. It was an enjoyable experience and provided new skills in the design and moderation of online fora. Overall, the perspectives of forum participants supported much of the views of patients and health professionals expressed in Phase 1 and 2 of the study. This suggests that some of the findings in the current study are comparable with experiences beyond South Wales. This study has also shown that discussion fora can

be an effective method of obtaining data. Yet a key consideration for this methodology is the strategy used to maximise participation. The literature about online focus groups (Sweet, 2001; Bloor *et al.*, 2002) and the use of discussion fora for teaching purposes (Salmon, 2003) provided useful advice about holding discussions online, yet neither addressed the methods used in this study. The following observations address issues that should be given consideration for setting up future online discussion fora.

Ownership of the discussion forum by participants is key to promoting participation. Issues that would appear minor, such as selection of a personalised username and password, can have a considerable effect on usage. Enabling users to create their own username and password not only provides a personal touch, but also has practical benefits as users are more likely to remember these details and log on. It is important to maintain the balance between motivating participants and placing undue pressure on people to participate. In this study, registered users were sent reminders about the forum. This strategy could have been coupled with details of the postings on the forum to encourage users to contribute. This approach was considered; however there was concern that users may read the postings in the e-mail and not access the forum, further reducing the likelihood of a reply to the discussion threads.

This study used a mixed method design. The rationale for the research design and decision making was discussed in Chapter Three. Each phase of data collection was used to inform the subsequent phase. This form of triangulation of data provided a useful way to validate the findings in each phase. Overall, the use of quantitative and qualitative methods provided an effective and appropriate way of meeting the aim of this study.

8.3 Achieving the study objectives and contribution to knowledge

The current study provided further evidence to substantiate that the internet is widely used as a source of health information for a diverse range of purposes. It also confirms that the digital divide continues to exist and a gender divide is prevalent in the management of health care. This study has been able to contribute to knowledge on patients' use of health information, including the internet in the following ways:

- Internet use has been examined within a framework of patient-centredness. On the basis of this study, the internet clearly has the potential to facilitate patient-centredness in primary care, yet there is little evidence of this happening in current practice;

- A detailed exploration of patient perspectives on use of the internet has been provided which supplements the existing literature that largely emphasises the views of health professionals and academics;

- This study offers a comparative view of internet use in primary care from patients and health professionals' perspectives;

- A primary care patient profile was constructed based on the use of health information by primary care patients in this study. This profile provides a useful tool to gauge the differing health information needs of primary care patients;

- In terms of methodological contributions, this study includes the design of an online discussion forum as a means of data collection. To the best of this researcher's knowledge, the method of investigation used in this study has not been previously reported within the literature;

8.4 Recommendations

Following these conclusions a number of recommendations are proposed for policy practice, and research.

8.4.1 Policy

It is contended that future policy directives need to consider:

- Strategies to promote and facilitate patient-centred approaches in primary care that involve ICT such as the internet. The aim here would be to consider ways of implementing existing policies by making the public aware that taking more control of their health is supported by health professionals and the government; (for example by developing further innovations such as the Expert Patient Initiative).

- Support and funding for patient associations/networks, particularly those that have provision online and who help others to get online;

- Further increase in internet provision (in health care settings) and training for the public, principally those in more deprived areas;

- Greater consumer involvement in devising patient information (developed by health professionals, the public and the voluntary sector) that is intended for websites. This approach has been adopted successfully for more traditional sources such as leaflets;

- The development of strategies to promote greater health awareness from sources other than health professionals. Particular attention should be focussed on promoting awareness in older patients, men and those with a low socio-economic status;

8.4.2 Practice

- The introduction of local ICT training programmes for primary care health professionals and patients that includes internet training and appraisal of evidence. Ideally, this should be guided by a needs assessment survey to determine the ICT training requirements in order to offer a tailor-made training programme;

- In recent years, medical training has included more humanities based subjects in the curriculum, which focus on enhancing communication skills. Continuing development of patient management skills for qualified practitioners in the light of new technologies is important to facilitate the development of the therapeutic alliance and promote patient-centred care;

- A list of medically accredited websites for common chronic conditions and lifestyle issues would be helpful for professionals and patients in primary care;

- The increased provision of primary care health promotion/advice drop-in sessions to service the role of practice nurses and nurse practitioners in facilitating patients in their need for better health information. Appropriate training should be given.

8.4.3 Research

This study investigated how primary care patients make use of health information sources with a particular focus on the internet. In doing so, it has also raised new questions that warrant further research.

- Observational research to examine how patients search for internet health information. This research would provide additional evidence to support the experiences of patients in this study. Existing observational research is in short supply and is confined to small sample sizes;

- Research into whether patients use information acquired from the internet to enhance a healthy life-style, for example, through self-monitoring of illness and how they do so.

- Further research into the feasibility of internet 'focused' consultations in primary care, possibly through the use of simulated consultations initially which take account of both the professional and the patient experience equally;

- Additional research into the quality indicators that patients use to assess websites and the relative weightings they accord each;

- Research with patients in the community who may use the internet as an alternative (including the use of alternative practitioners) to accessing conventional health services. including an exploration of their reasons for doing so.

- To investigate ways in which use of the internet can be promoted to non-users.

8.5 Concluding remarks

Prior to this study, the internet was viewed as a 'hot potato' in relation to health information, frequently cited as having the potential to trigger hostility in doctor-patient consultations. There were also claims that patients were being misinformed, or put at risk by accessing the internet. In 1999, Jadad predicted a rapid transition in the internet age that would present many challenges. He contended that these challenges would only be addressed, '*...through innovative alliances...optimal communication and access to high quality, relevant information at the right time in the right place...*' (Jadad, 1999, p 765). Considerable progress has been made since the last decade. This study has highlighted that although the internet is a valuable resource that can facilitate patients to take greater responsibility for their health, in some contexts it differs little from more traditional sources of information.

This study has offered further insight into patients' use of the internet in primary care. From a policy perspective, it is encouraging that some patients are committed to gaining more knowledge about their health and are becoming more involved in decisions about their own health. The internet is a powerful resource which can assist patients to expand their knowledge, share their experiences of illness and consider new or alternative forms of treatments. The internet does however have some limitations. The quality and relevance of the information to the individual are often questionable. It is promising that patients in this study felt more comfortable if they could discuss internet information with a health professional.

A central focus of this study was to consider the differences in use of the internet for health according to socio-economic status. The internet is perceived by patients and professionals (given the right context) as an effective tool to access health information. There are still many sectors of society that do not have access to the internet and so it is important to consider whether they may be disadvantaged by being excluded from this resource. It will also be an interesting challenge in the future to determine how the internet could be used to provide supplementary health information for those of lower socio-economic status.

Clearly, there has been a change in the distribution of accountability of patients' health care management. It would appear that the increase in regulation such as risk management and clinical governance and the drive towards patient-centred care is moving from a doctor-centred to a patient-centred approach in the provision of care. This situation may be desirable for many patients, yet experiences of patients in this study show that although they are active seekers of health information; they ultimately rely on their doctor for health care management. Seemingly, a consultation based on negotiation would determine how each of these partners wished to interact. Evidence from this study indicates that the internet can facilitate patient-centredness, but can also complicate the doctor-patient relationship.

Patients' experiences in this study support the policy drive towards greater involvement in their health, although their experiences suggest that this has yet to be realised in their primary care environment. It is important to be realistic about these goals as achieving more patient-centred approaches requires a change in beliefs about the expectations of patient-professional encounters. A proportion of primary care patients may embrace the opportunity to be more autonomous in their role by gaining internet information to supplement that received from health professionals. However, it may prove more difficult to shift the boundaries of the traditional consultation. In their recent curriculum statement the RCGP offer strong support for person-centred care which is described as, *'...more than just a way of acting; it is a way of thinking'* (RCGP, 2005b, p7). Health professionals may therefore facilitate this process by adjusting to change. However, patients may also need to relinquish aspects of their 'patient' status and act as knowledgeable partners in managing their care in order to fully embrace the notion of patient-centredness.

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APPENDIX 1

CONFERENCE PRESENTATIONS AND JOURNAL PUBLICATIONS

Journal publications

Dolan, G. (2003) How do patients make use of health-related information from the Internet? Investigating the views of the public and healthcare professionals. *International Journal of Consumer Studies* 27 (3): 241 (Abstract).

Dolan, G., Iredale, R., Williams, W.R. & Ameen, J. (2004) Consumer use of the Internet for health information: a survey of primary care patients. *International Journal of Consumer Studies* 28 (2): 147-153.

Dolan, G., Iredale, R., Williams, W.R. & Ameen, J. (2004) Patients' use of health information on the internet: the impact on primary care consultations *Technology and Healthcare* 11 (5): 304-305 (Abstract).

Oral presentations

Dolan, G. How do patients make use of health-related information from the internet? Investigating the views of the public and healthcare professionals. *First Annual Doctoral Seminar.* University of Glamorgan, 7th December 2001.

Dolan, G. How do patients make use of health-related information from the Internet? Investigating the views of the public and healthcare professionals. *Wales RCGP Primary Care Symposium, Research and Development Day.* December 2002, Cwrt Bleddyn Hotel, Usk.

Dolan, G., Iredale, R., Williams, W.R. & Ameen, J. (2003) Patients and the internet – a new perspective *1st Institute of Consumer Sciences (incorporating Home Economics) Research Conference, Empowering the Consumer in the 21st Century.* UWIC, Llandaff Centre.

Dolan, G., Iredale, R., Williams, W.R. & Ameen, J. (2003) Patients' use of health information on the internet: the impact on primary care consultations. *Internet in Health for All. Mednet 2003, 8th World Congress on the Internet in Medicine, University Hospital Geneva,* 4-7 December.

Invited speaker

Dolan, G. Consumer use of the internet- what do they do online? *NHS Direct, Hedge End, Hampshire.* Research Seminar Series June 2004

Poster presentations

Dolan, G. How do patients make use of health-related information from the Internet? Investigating the views of the public and healthcare professionals. *Telemedicine & Ehealth Forum: TeleMed '02,* The Royal Society of Medicine, 29-30 January 2002.

Dolan, G. (2002) How do patients make use of health-related information from the Internet- a survey of primary care patients. *Wales RCGP Primary Care Symposium, Research and Development Day.* December 2002, Cwrt Bleddyn Hotel, Usk.

Dolan, G., Iredale, R., Williams, R.W. & Ameen, J. The impact of the internet on primary care consultations. *3rd-4th March 2005 South West Primary Care Conference,* Hanover International Hotel, Cardiff.

APPENDIX 2

POLICY TIMELINE

Policy Timeline

1998
DoH (1998) Information for Health.
Welsh Office (1998) Better Health Better Wales.
Welsh Office (1998) Putting Patients First.

2000
DoH (July 2000) The NHS Plan: A Plan for Investment, a plan for reform.

2001
DoH (May 2001) Building the Information Core – Implementing the NHS Plan.
DoH (May 2001) Information Implications of Shifting the Balance of Power.
NAfW (2001) Improving Health in Wales: A Plan for the NHS with its Partners.
NAfW (2001) Improving Health in Wales: The Future of Primary Care.
DoH (2001) The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century.
NAfW (2001) Cymru Ar-lein: Welsh IT strategy.

2002
Wanless, D (2002) Securing Our Future Health: Taking a Long-term View.
DoH (June 2002) Implementing Information for Health (England).
WAG (2002) Informing Healthcare.
WAG (2002) Well Being in Wales.
DoH (2002) Delivering 21st century IT support for the NHS; National strategic Programme.
WAG (2002) The Action Plan for Primary Care in Wales.

2003
BMA (2003) General Medical Services Contract (E &W).
DoH (2003) Building on the Best: Choice, Responsiveness and Equity in the NHS.
Wanless, D. (2003) Review of Health and Social Care in Wales.
Audit Commision (2003) Transforming Health and Social Care in Wales

2004
DoH (2004) Patient and Public Involvement in Health: The Evidence of Policy Implementation.
DoH (2004) NHS Improvement plan: Putting People at the Heart of Public Services.
DoH (2004) 'Getting over the wall' How the NHS is Improving the Patient's Experience.
DoH (2004) Better Information, Better Choices, Better Health.

2005
DoH (2005) Self Care – A Real Choice.

APPENDIX 3

PRACTICE PROFILE

Practice 1

The first practice is a large urban practice situated on the outskirts of Cardiff City. At the time of the study there were 16,500 patients registered at the practice. A large number of staff are employed at this practice which provides a wide range of services for their patients. A description of all staff is listed in Table 1.

Table 1: Staff employed in Practice 1

Position held	**Frequency**
Full-time GP	8
Part-time GP	4
Nurse Practitioner	1
Practice Nurse	4
Research Nurse	1
District nurses	Team
Health Visitors	2
Social Worker	1 (employed by local authority)
Midwives	2
Reception staff	8
Administrative staff	9
Practice Manager	1
Total	**41**

The main practice operates general surgery on an appointment basis. Patients can make an appointment to see a GP or Nurse Practitioner from 8.30 to 10.40 a.m. and from 3.00 to 5.10 p.m. Practice nurses are available for appointments from 9.00 to 1.00pm and 2.00 to 5.30pm. Patients can attend for emergency appointments at the end of normal surgery time, if necessary, on a first come first served basis. A range of clinics are held throughout the day which focus on areas such as Antenatal, Asthma, Child development, Diabetes, Dietetics, Family planning, Health Promotion, Hypertension, Minor surgery, Over 75s, Pregnancy bookings (double appointment) and Well Baby. The surgery is open on Saturday morning for emergency appointments. The practice has a Branch surgery nearby which operates on slightly reduced hours to the main surgery.

Practice 1 is a paperless practice with computers (online) in all consulting rooms/offices.

Practice 2

Practice 2 is a smaller semi-rural practice located in the Valleys of South Wales. At the time of the study 6,500 patients were registered at the practice. The practice is run by 3 full-time GPs and two practice nurses. There are 4 reception staff and a practice manager. Appointments for general surgery are available from 9.00 to 11.00 and from 3.30 to 5.30 with the exception of Thursday afternoon when the surgery is closed. Patients can attend for an emergency appointment at the end of general surgery on first come first served basis. Appointments are available at a variety of clinics in the afternoon. These include, Ante-natal, Asthma, Diabetes, Hypertension and Post-natal. The surgery is also open on Saturday morning for emergency appointments. This practice operates a branch surgery nearby. Table 2 shows the range of staff employed in Practice 2.

Table 2: Staff employed in Practice 2

Position held	Frequency
Full-time GP	3
Practice Nurse	2
District nurses	Team
Health Visitors	1
Social Worker	1
Midwives	2
Reception staff	4
Administrative staff	3
Practice Manager	1
Total	17

There are computers (online) in all consulting rooms/offices in Practice 2.

A notable difference between these practices is their size. Practice 1 is over twice the size of Practice 2. In terms of services available to patients, the practices offer similar care for their patients however Practice 1 does have a Nurse Practitioner. Where possible any differences which may impact on the data will be addressed at the data analysis stage.

APPENDIX 4

INTERIM LETTER

University of Glamorgan

Prifysgol Morgannwg

October 27th 2002

Dear

Re: Research study investigating patient use of health information

My name is Gina Dolan and I am a researcher from the University of Glamorgan. You may remember that you kindly completed a questionnaire at your GP surgery a few months ago, about your use of health information. On the questionnaire you indicated that you may be interested in taking part in an interview at the surgery to discuss your use of health information in more detail. I am hoping to conduct the interviews at your surgery during the next couple of weeks and was wondering if you are still interested in taking part.

The interview will last approximately 30 minutes. Participation is voluntary but if you decide to take part you are still free to withdraw at any time without giving a reason. All of the information collected will be confidential and anonymous.

I have been unable to contact you by telephone and would therefore appreciate it if you could contact me by phone or letter in the next few days to let me know if you are interested and available for interview.

Thanks in anticipation

Yours Sincerely

Gina Dolan

APPENDIX 5

PATIENT INFORMATION

Verbal introduction for patients

My name is Gina Dolan; I am a researcher from the University of Glamorgan. I am conducting a survey this morning about patients' use of health information and wondered if you would be interested in taking part. You do not have to take part in this research, but your participation would be greatly appreciated.

Any information provided will be confidential and your name will not appear anywhere in the research report.

Further details about the study are provided on the patient information sheet attached to the survey.

Please let me know if you have any further questions.

Thank you for your time.

Study: *Patients use of health information*

Your surgery is taking part in a research study to find out about patients' use of health information. I am approaching all patients attending the surgery this week to see if they will assist me in this study by completing a brief questionnaire.

This study aims to find out about which sources of information (including the Internet) you use to obtain information about health. It will involve you completing a questionnaire at the surgery today, which will take about 5-10 minutes.

Participation is voluntary but if you decide to take part you are still free to withdraw at any time without giving a reason. All of the information collected will be confidential and anonymous.

It is important that you understand why we are doing this research and what it will involve before you decide if you want to take part. Please let me know if you have any questions before you decide if you would like to take part.

Thank you for your time

Gina Dolan

Research Assistant

University of Glamorgan

Patient Information sheet1/ August 2001

Patient information sheet (Interview)

Study: Patients use of health information on the Internet

I would like to thank you for completing a questionnaire recently at your surgery about the use of health information on the Internet. I would also like to interview you to discuss your use of health information in more detail. The interview will be conducted in the surgery and will last approximately 30 minutes.

Participation is voluntary but if you decide to take part you are still free to withdraw at any time without giving a reason. All of the information collected will be confidential and anonymous.

It is important that you understand why we are doing this research and what it will involve before you decide if you want to take part. Are there any questions you would like to ask before you decide if you would like to take part?

Do you agree to take part?

Thank you for your time

Gina Dolan
Research Assistant
University of Glamorgan

APPENDIX 6

STAFF INFORMATION

Staff Information Sheet

Study: Patients use of health information on the Internet

My name is Gina Dolan, I am a researcher from the University of Glamorgan. Dr XX may have discussed with you that the surgery is taking part in a research study involving the use of health information on the Internet. I am approaching some members of staff to take part in the study.

This study aims to find out your views about the sources of information patients use (including the Internet) to obtain information about health. It will involve you taking part in a brief semi-structured interview, at the surgery, which will last approximately 30 minutes.

Participation is voluntary but if you decide to take part you are still free to withdraw at any time without giving a reason. All of the information collected will be confidential and anonymous.

It is important that you understand why we are doing this research and what it will involve before you decide if you want to take part. Please contact me if there are any questions you would like to ask me before you decide if you would like to take part?

Thank you for your time.

Gina Dolan

Research Unit

School of Care Sciences

APPENDIX 7

DISCUSSION FORUM FLYER

On-Line Discussion Forum

Why do patients use the Internet for information about health and disease?

Are you interested in why they use it?

What are your views about patients who bring in Internet information to discuss in consultations?

How can healthcare professionals respond to Internet informed patients?

What's the issue?
If any of the above or similar questions interest you, then you might be interested in a new on-line discussion forum beginning in January 2004. Researchers at the University of Glamorgan in Wales (UK) are exploring patients' use of health information from the Internet. We are interested in canvassing a wide range of opinion on this topic and we hope to make recommendations about the ways in which the health information needs of patients in primary care can be met.

The Forum
An on-line discussion group will be set up starting from Monday 5th January to mid February, where groups of experts can log on and talk through the relevant issues. The forum will include experts from the fields of primary care; health service management; consumer groups and academia.

Why you?
You have been identified as someone having an interest in the area of consumer health informatics and healthcare policy. We would greatly value the contribution you could make to this project.

How can you help?
From Monday January 5th you can register for the discussion group.

Please contact Gina Dolan on gcdolan@glam.ac.uk or 01443 483815 for further information and details about how you can register.

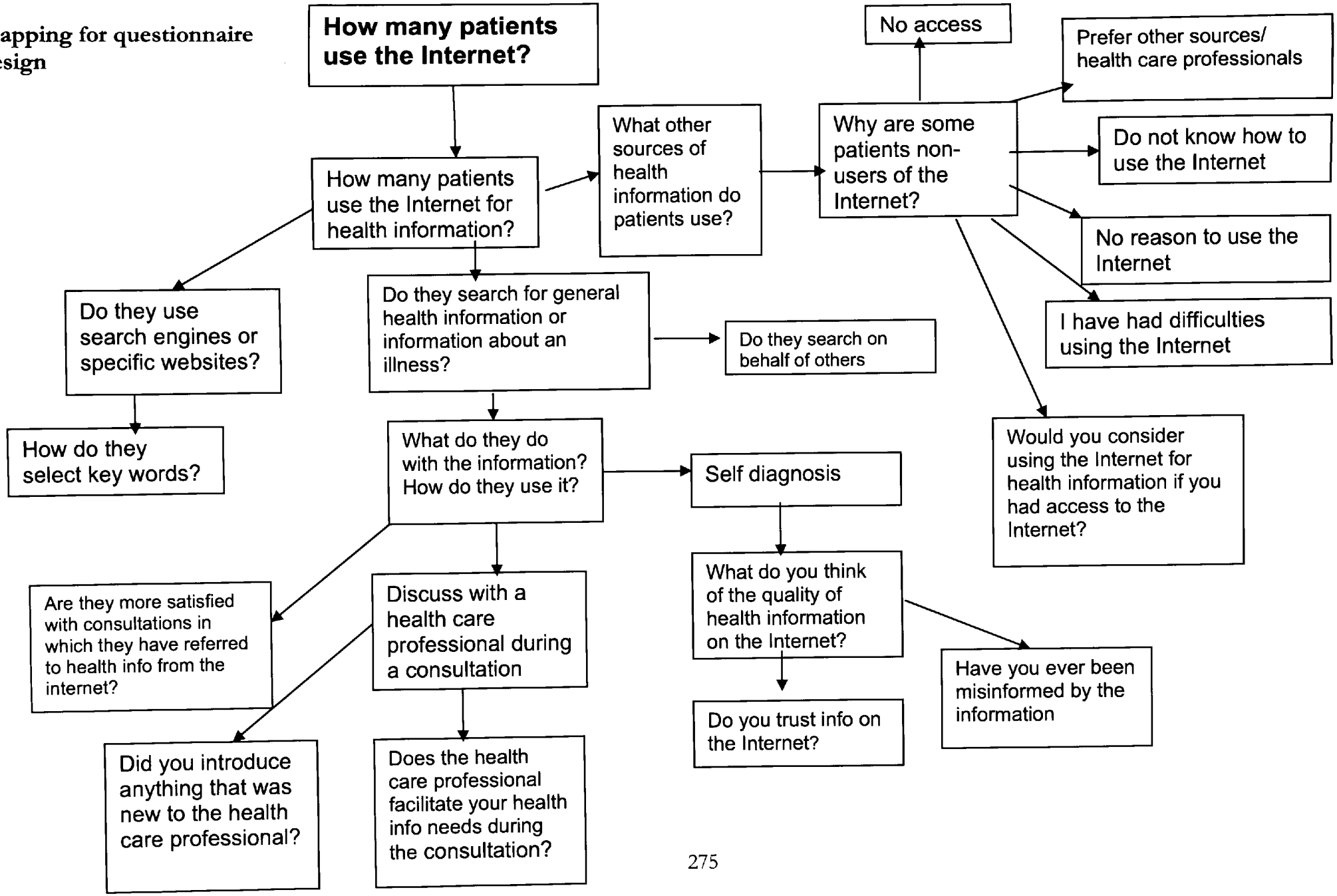
University of Glamorgan

you live, you learn

APPENDIX 8

MAPPING EXERCISE

Mapping for questionnaire design



APPENDIX 9

HEALTH VALUE SCALE

HEALTH VALUE SCALE

NFER-NELSON
Health & Social Care

Name: .....

Date: ..... **Record Number:** .....

Indicate the extent to which you agree with the following four statements, using the scale below. Write the appropriate number in the blank space to the right of each statement.

Strongly agree		*Moderately agree*		*Moderately disagree*		*Strongly disagree*
1	2	3	4	5	6	7

1) There is nothing more important than good health. ☐

2) Good health is only of minor importance in a happy life. ☐

3) If you don't have your health, you don't have anything. ☐

4) There are many things I care about more than my health. ☐

APPENDIX 10

PATIENT QUESTIONNAIRE

PATIENT SURVEY OF SOURCES OF HEALTH INFORMATION

1.Which of the following sources of health information have you used during the past 6 months?

(Please tick as many boxes as apply for each source that you have used to seek information about an illness, or general health information

	For information about an illness	For general health information (e.g. diet, exercise)
1. TV	☐	☐
2. Radio	☐	☐
3. Magazines	☐	☐
4. Newspapers	☐	☐
5. Medical/health journals	☐	☐
6. Books	☐	☐
7. Leaflets	☐	☐
8. Friends/relatives	☐	☐
9. Telephone advice line (e.g. NHS Direct)	☐	☐
10. Doctor	☐	☐
11. Nurse	☐	☐
12. Health visitor	☐	☐
13. Midwife	☐	☐
14. Pharmacist	☐	☐
15. Internet	☐	☐
16. Other _____ (please state)	☐	☐

2. Please state ONE source of health information from the list above that you use most often?

For information about an illness _____

For general health information _____

3. What is your preferred source of health information? _____

4. Do you ever use any of the sources from the list above during consultations with health care professionals? No ☐

Yes ☐

5. If yes, please state the source you use most often _____

6. Do you have access to the Internet?

- ☐ Yes
- ☐ No — If no, go to question 13

7. Where do you use the Internet?
(Please tick all the boxes that apply)

- ☐ At home
- ☐ At your place of work/study
- ☐ At an Internet café
- ☐ At a public library
- ☐ Other (please state)_____

8. How long have you been using the Internet?

Less than 6 months	☐
6-12 months	☐
1-2 years	☐
3-4 years	☐
5+	☐

9. Have you ever used the Internet to access information about health? Yes ☐ No ☐

If no, go to question 12

10. Have you ever discussed health information obtained from the Internet during a consultation with a health care professional? Yes ☐ No ☐

If no, go to question 13

11. Which of the following statements represents your views about using health information from the Internet during a consultation?

	Yes	No
I feel that I can participate more in decisions about treatment and care	☐	☐
The consultation time increases	☐	☐
I feel more prepared	☐	☐
My health care professional listens more to what I have to say	☐	☐
I have introduced information that is new to the health care professional	☐	☐
The consultation is more effective	☐	☐
I trust my health care professional more than the Internet	☐	☐

Now go to question 13

12. Which of the following reasons stop you from using the Internet for health information?

	Yes	No
If I want health information I would ask a health care professional	☐	☐
I prefer to use other sources of health information	☐	☐
I have tried using the Internet and have not found the information useful	☐	☐
I find the information too difficult to understand	☐	☐
I do not know how to use the Internet	☐	☐
I have no reason to use the Internet	☐	☐
I do not trust health information on the Internet	☐	☐

13. Indicate the extent to which you agree with the following four statements, using the scale below. Write the appropriate number in the blank space to the right of each statement.

Strongly agree		*Moderately agree*		*Moderately disagree*		*Strongly disagree*
1	2	3	4	5	6	7

1) There is nothing more important than good health ☐

2) Good health is only of minor importance in a happy life ☐

3) If you don't have health, you don't have anything ☐

4) There are many things I care about more than my health ☐

Finally, a few questions about you:

14. How old are you? (Please state) _____

15. GENDER Male ☐ Female ☐

16. Are you currently: (Tick one box only)
Employed ☐
Unemployed ☐
Retired ☐
Student ☐
Other ☐ Please state _____

17. If applicable, please state your present or former occupation _____

18. Please tick your highest level of qualification from the list below:

GCSE ☐ (O-level/CSE/ school certificate)
GNVQ/NVQ ☐
A-level/AS level ☐
First Degree ☐
Higher degree ☐ (MSc, PhD, post-graduate certificate, diploma)
Other qualifications ☐
No qualifications ☐

19. Please state if you have any professional qualifications? *(e.g. nursing, teaching)*_____

PATIENT INTERVIEWS

I would like to talk to a small number of respondents in more detail about aspects of use of the Internet for health information (users and non-users of the Internet are eligible to take part). I would be very grateful if you would be willing to take part in a brief interview (approximately 30 minutes), which will take place at the surgery. You are under no obligation to take part and non-participation will not affect the care you receive in any way. Participation is voluntary but if you decide to take part you are still free to withdraw at any time without giving a reason. All of the information collected will be confidential and anonymous. Please let the researcher know if you have any questions before you decide if you would like to take part.

If you are willing to take part in a brief interview during the next few weeks, please fill out your contact details below:

Name:

Telephone number:

Address:

	Yes	No
Do you use the Internet?	☐	☐

E-mail:

If you agree, I may contact you during the few weeks to arrange an interview.

PLEASE PLACE COMPLETED QUESTIONNAIRES IN THE BOX PROVIDED IN THE RECEPTION AREA

APPENDIX 11

INTERVIEW SCHEDULES

Patient interview schedule

The purpose of this interview is to discuss the sources of information you use to obtain information about health/medical issues.

Just to remind you that I will be tape recording the discussion. All of the information discussed will be entirely confidential and anonymous. This information will be used for research purposes only. Your name will not appear on any of the publications from the project. All of the taped interviews will be erased on completion of the project.

Schedule 1: Health Internet users

1. To start off with can you describe the last time you needed information about a health issue?

2. What are the main sources you use to obtain information about your health?

3. Which of the sources do you find most useful? And why?

4. How frequently do you seek health information from each of these sources?

5. How do you use the health information which you access? Do you tend to access general health information, or focus on particular illnesses/conditions?

6. Do you use the Internet to access information about health? If yes, can you tell me about the ways in which you use it? Have you used it for your own/ someone else's health?

7. Where is the main place you have access to the Internet?

8. How long have you been using the Internet? How long for health information?

9. What sort of health information do you search for on the Internet? General searches, treatments, diagnosis, health monitoring, lifestyles?

10. How do you search for information? e.g. do you use the search engines or do you use web sites that you have the addresses for?

11. Do you seek health information on the Internet for others e.g. family/friends?

12. Do you find it easy to obtain what you are looking for?

13. In general how easy do you find the information to understand?

14. What initiates your search for health information on the Internet?

15. How do you use the information you obtain from the Internet?

16. Do you discuss the information from the Internet with health professionals? Who? If so do you find this useful in any way?

17. How do you think they feel about discussing this information during a consultation?

18. Is there any way that health professionals could facilitate your use of health information from the Internet?

19. Are there any benefits of using the Internet for health information? If so what are they?

20. Are there any limitations in using the Internet for health information?

21. Is there anything that could help make your use of the Internet for health information easier?

22. Are there any other comments you would like to make?

Schedule 2: Non-health Internet users

1. To start off with can you describe the last time you needed information about a health issue?

2. What are the main sources you use to obtain information about your health?

3. Which of the sources do you find most useful? And why?

4. How frequently do you seek health information from these sources?

5. How do you use the health information, which you access? Do you tend to access general health information, or focus on particular illnesses/conditions?

6. Where is the main place you have access to the Internet?

7. How long have you been using the Internet?

8. What factors have influenced your decision not to use the Internet to access health information?

9. Does anything prevent you from accessing health information on the Internet?

10. Are you concerned about the quality of the information?

11. Are you aware of any Internet sites for health information?

12. Do you think that the Internet could be a valuable source of health information?

13. Is there anything that would encourage you or facilitate you to use the Internet for health information?

14. Are there any other comments you would like to make?

Schedule 3: Non-users of the Internet

1. To start off with can you describe the last time you needed information about a health issue?

2. What are the main sources you use to obtain information about your health?

3. Which of the sources do you find most useful? And why?

4. How frequently do you seek health information from these sources?

5. How do you use the health information, which you access? Do you tend to access general health information, or focus on particular illnesses/conditions?

6. Have you ever accessed the Internet for any type of information? If no why?

7. If yes, what information? Did you find the Internet useful?

8. If you had access to the Internet what sorts of things would you use it for?

9. Would you use it to access information about health?

10. Can you think of any advantages/disadvantages from using health information from the Internet?

11. Do you think you will use the Internet for information in the future?

12. Are there any other comments you would like to make?

Staff interview schedule

The purpose of this interview is to discuss the sources of information you use to obtain information about health. This includes the use of information for both personal and professional purposes. This interview will also explore patients' use of health information.

Just to remind you that I will be tape recording the discussion. All of the information discussed will be entirely confidential and anonymous. This information will be used for research purposes only. Your name will not appear on any of the publications from the project. All of the taped interviews will be erased on completion of the project.

1. What are the main sources of health information that you use in your role as a health professional?

2. What health information sources do you use for personal use?

3. Can you describe the last time you needed information about a health issue?

4. How frequently do you seek health information from each of these sources?

5. Where do you tend to access these sources?

6. Are there any sources that you find particularly useful, and if so why?

HCP use of Internet

7. Do you use the Internet to access health/medical information? If yes, where is the main place you access the Internet? Access to net in practice?

8. How long have you been using the Internet for health information?

9. What type of information do you access from the Internet? e.g. treatments, diagnoses, drugs.

10. Are they any health web-sites, which you prefer to use?

11. Do you find it easy to obtain what you are looking for?

12. Do you find the information relevant to your needs?

13. Do you have a computerised system at the surgery? If so, do you ever use your computer during a consultation to search for information? Or do you have/use disease management systems-are they useful?

Patients' use of health information (Internet)

1. What type of information sources do you think patients use?

2. Do you think patients prefer to use particular sources of health information?

3. Do patients discuss any information sources with you during a consultation?

4. Do patients discuss health information they have accessed from the Internet? If yes, how often? What do you think about Internet informed patients?

5. How do you feel about patients who bring in or refer to health information during a consultation? Do you/they find these discussions useful?
   Can you remember a particular case – what happened?

6. Are you aware of any web-sites that have been developed for use by patients?

7. Are you aware of any NHS services for patients that have web pages?

8. Do you ever refer patients to the Internet? If so, what sort of information do you give them? Key words, websites, support groups.

9. Have you ever used on on-line consultation service – (are you aware of it)?

The Internet as a source of health information for patients

1. Are there any benefits/limitations of patients using the Internet for health information?

2. Why do you think that some patients who have access to the Internet choose not to use it for health?

3. Is there anything that could help make using the Internet for health information easier?

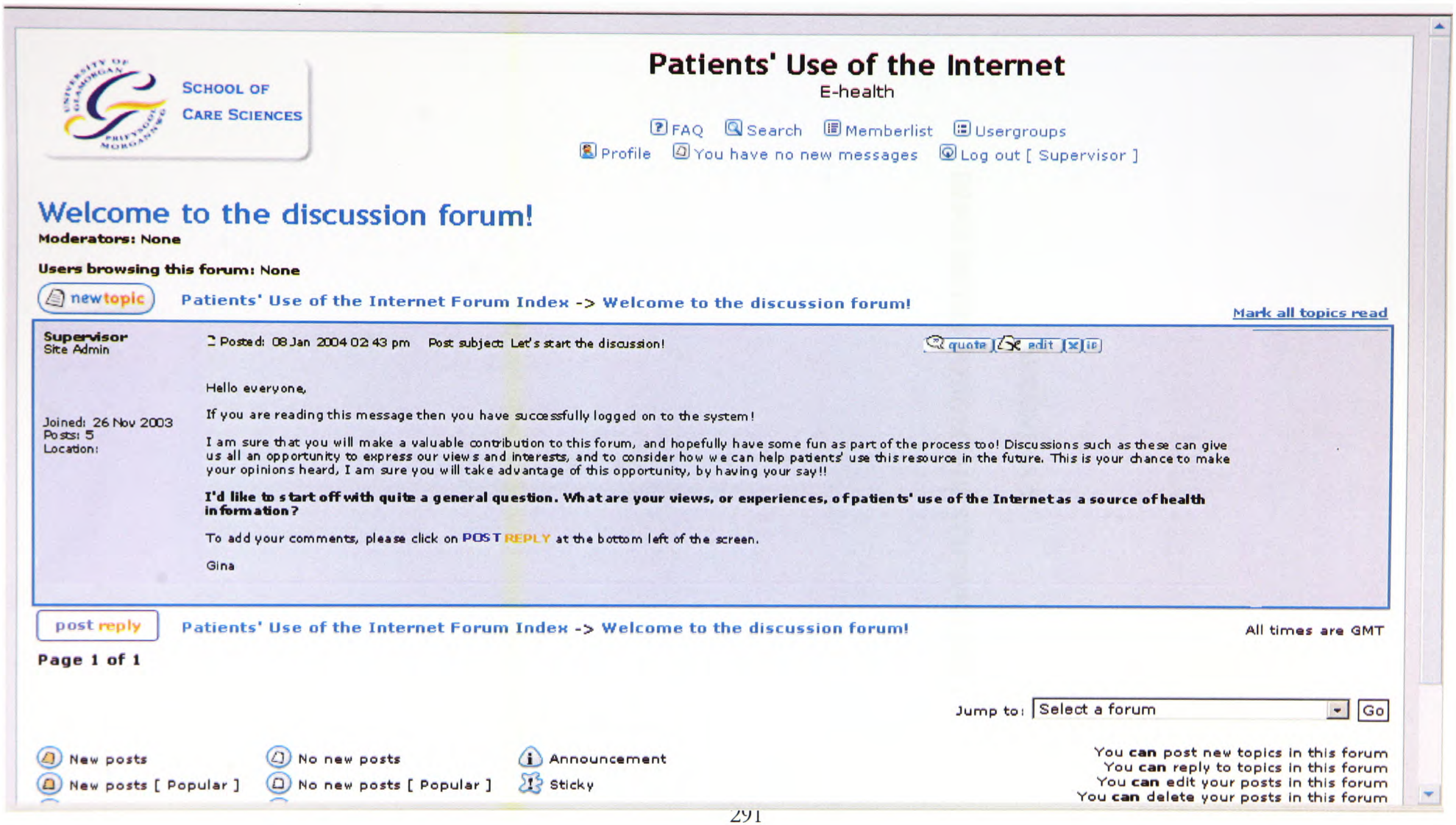
4. What do you think about providing public access to health information on the Internet? e.g. at surgeries, libraries, schools.

5. How do you think future trends in using the Internet for health will develop?

6. Are there any other comments you would like to make?

APPENDIX 12

SCREEN SHOT OF DISCUSSION FORUM


SCHOOL OF
CARE SCIENCES
Patients' Use of the Internet
E-health
FAQ
Search
Memberlist
Usergroups
Profile
You have no new messages
Log out [Supervisor]
Welcome to the discussion forum!
Moderators: None
Users browsing this forum: None
newtopic
Patients' Use of the Internet Forum Index -> Welcome to the discussion forum!
Mark all topics read
Supervisor
Site Admin
Posted: 08 Jan 2004 02:43 pm
Post subject: Let's start the discussion!
quote
edit
ip
Joined: 26 Nov 2003
Posts: 5
Location:
Hello everyone,
If you are reading this message then you have successfully logged on to the system!
I am sure that you will make a valuable contribution to this forum, and hopefully have some fun as part of the process too! Discussions such as these can give us all an opportunity to express our views and interests, and to consider how we can help patients' use this resource in the future. This is your chance to make your opinions heard, I am sure you will take advantage of this opportunity, by having your say!!
I'd like to start off with quite a general question. What are your views, or experiences, of patients' use of the Internet as a source of health information?
To add your comments, please click on POST REPLY at the bottom left of the screen.
Gina
post reply
Patients' Use of the Internet Forum Index -> Welcome to the discussion forum!
All times are GMT
Page 1 of 1
Jump to:
Select a forum
Go
New posts
No new posts
Announcement
New posts [Popular]
No new posts [Popular]
Sticky
You can post new topics in this forum
You can reply to topics in this forum
You can edit your posts in this forum
You can delete your posts in this forum

APPENDIX 13

DISCUSSION FORUM QUESTIONNAIRE

SCHOOL OF
CARE SCIENCES

Gina Dolan Questionnaire

Patients' use of the Internet - Feedback questionnaire.

Your Name :

Your E-Mail :

1. Discipline.

Please select one of the following options

1	Health professional	☐
2	Academic	☐
3	Government/Policy	☐
4	Consumer Groups	☐
5	Health Technology	☐
6	Other (please specify below)	☐
	Other (Please Specify :)	

2. Please enter the name of your institution.

3. Please enter the name of the country in which your institution is based.

4. Have you accessed the discussion forum ?

Yes	No
☐	☐

5. If your response to Question. 4 is 'no', which of the following reasons prevented you from accessing the forum? (Please tick any applicable boxes). Go to question 10.

1	Problem with link to web site.	☐
2	Password problems	☐
3	Not interested in the discussion topics	☐
4	Too Busy	☐
5	Limited access to Internet	☐
6	Others (Please Specify :)	

6.Did you read the messages on the forum?

Yes	No
☐	☐

7.Did you post any messages

Yes	No
☐	☐

8. If no, please state the main reason why you didn't post a message on the forum.

9. What are your general views about using my discussion forum? Was there anything that you particularly liked or disliked? Do have any suggestions for possible improvements

10. Finally, a general question about the forum topic. How do you predict patients' use of the Internet will develop over the next 10 years ?

Thank you for taking the time to complete this questionnaire, it is much appreciated. All information will be treated in confidence and used ONLY for the purpose of research.

Submit Reset

APPENDIX 14

SPSS PROGRAMME

TITLE 'Patient Filter Survey Pilot 2001'.

```
DATA LIST RECORDS = 3 FILE ='N:\GCDOLAN\PhD\SPSS\RAW
DATA\PATIENTSURVEY.TXT'
/1 ID 1-3
/2 TVILLN 1 TVINFO 2 RADIILLN 3 RADIINFO 4 MAGIILLN 5
MAGIINFO 6 NEWSILLN 7 NEWSINFO 8 JOURILLN 9 JOURINFO 10
BOOKILLN 11 BOOKINFO 12 LEAFILLN 13 LEAFINFO 14 FRELILLN 15
FRELINFO 16 TELEILLN 17 TELEINFO 18 DOCRILLN 19 DOCRINFO 20
NURSILLN 21 NURSINFO 22 HVISILLN 23 HVISINFO 24 MIDWILLN 25
MIDWINFO 26 PHARILLN 27 PHARINFO 28 INETILLN 29 INETINFO 30
OTHEILLN 31 OTHEINFO 32 USEFILLN 33-34 USEFINFO 35-36
PREFSOUR 37-38 INFOCONS 39 CONSPREF 40-41 NETACCES 42
HOMEACCE 43 WORKACCE 44 CAFEACCE 45 LIBRACCE 46 OTHEACCE
47 TIMEUSED 48 EVERUSED 49 DISCUNET 50 PARTPATE 51
TIMEINCR 52 PREPARED 53 DRNLISTE 54 NEWINFOR 55 EFFECTIV 56
TRUSTDOC 57 ASKDRNUR 58 OTHSOURC 59 NETNOUSE 60 DIFFUNDE
61 NOTKNOWH 62 NOREASON 63 NOTRUNET 64 HEALTHIM 65
MINORIMP 66 NOHEALTH 67 CAREMORE 68
/3 AGE 1-3 GENDER 4 EMPLOYMT 5 OCCUPATN 6-7 HIGHQUAL 8
PROFQUAL 9 PRACTICE 10.

MISSING VALUES ID (999)/TVILLN TO OTHEINFO (9, 8)/ USEFILLN TO
PREFSOUR (99, 98)/INFOCONS NETACCES TO CAREMORE(9, 8)/AGE
(999)/GENDER TO PROFQUAL(9, 98, 99).

COMPUTE REVHEALT = 8 - HEALTHIM.
COMPUTE REVNOHEA = 8 - NOHEALTH.

COMPUTE HTHVALUE = REVHEALT + MINORIMP + REVNOHEA +
CAREMORE.
```

VARIABLE LABELS

ID 'Patient ID'

TVILLN 'TV for information about an illness'

TVINFO 'TV for general information'

RADIILLN 'Radio for information about an illness'

RADIINFO 'Radio for general information'

MAGIILLN 'Magazines for information about an illness'

MAGIINFO 'Magazines for general information'

NEWSILLN 'Newspapers for information about an illness'

NEWSINFO 'Newspapers for general information'

JOURILLN 'Journals for information about an illness'

JOURINFO 'Journals for general information'

BOOKILLN 'Books for information about an illness'

BOOKINFO 'Books for general information'

LEAFILLN 'Leaflets for information about an illness'

LEAFINFO 'Leaflets for general information'

FRELILLN 'Friends or relatives for information about an illness'

FRELINFO 'Friends or relatives for general information'

TELEILLN 'Telephone advice line for information about an illness'

TELEINFO 'Telephone advice line for general information'

DOCRILLN 'Doctor for information about an illness'

DOCRINFO 'Doctor for general information'

NURSILLN 'Nurse for information about an illness'

NURSINFO 'Nurse for general information'

HVISILLN 'Health visitor for information about an illness'

HVISINFO 'Health visitor for general information'

MIDWILLN 'Midwife for information about an illness'

MIDWINFO 'Midwife for general information'

PHARILLN 'Pharmacist for information about an illness'

PHARINFO 'Pharmacist for general information'

INETILLN 'Internet for information about an illness'

INETINFO 'Internet for general information'

OTHEILLN 'Other source for information about an illness'

OTHEINFO 'Other source for general information'

USEFILLN 'Which source of health information about your illness do you use most often'

USEFINFO 'Which source of general health information do you use most often'

PREFSOUR 'What is your preferred source of health information'

INFOCONS 'Do you use any sources of information during the consultation'

CONSPREF 'What source of information do you prefer to use during consultations'

NETACCES 'Do you have access to the Internet'

HOMEACCE 'Use the Internet at home'

WORKACCE 'Use the Internet at work'

CAFEACCE 'Use the Internet at a Internet café'

LIBRACCE 'Use the Internet at the Library'

OTHEACCE 'Other use of the Internet'

TIMEUSED 'How long have you used the Internet'

EVERUSED 'Ever used the Internet to access information about health'

DISCUNET 'Ever discussed health information from the Internet during a consultation'

PARTPATE 'I feel that I can participate more in decisions about treatment and care'

TIMEINCR 'The consultation time increases'

PREPARED 'I feel more prepared'

DRNLISTE 'My doctor/nurse listens more to what I have to say'

NEWINFOR 'I have introduced information that is new to the health care professional'

EFFECTIV 'The consultation is more effective'

TRUSTDOC 'I trust my health care professional more than the Internet'

ASKDRNUR 'If I want health information I would ask a doctor or nurse'

OTHSOURC 'I prefer to use other sources of health information'

NETNOUSE 'I have tried using the Internet and have not found the information useful'

DIFFUNDE 'I find the information too difficult to understand'
NOTKNOWH 'I do not know how to use the Internet'
NOREASON 'I have no reason to use the Internet'
NOTRUNET 'I do not trust the information on the Internet'
HEALTHIM 'There is nothing more important than good health'
MINORIMP 'Good health is only of minor importance in a happy life'
NOHEALTH 'If you dont have health you dont have anything'
CAREMORE 'There are many things I care about more than my health'
HTHVALUE 'Total health value score (Low (4) = negative Hi (28) = Positive'
AGE 'How old are you'
GENDER 'Are you male or female'
EMPLOYMT 'Employment status'
OCCUPATN 'What is your occupation'
HIGHQUAL 'What is your highest level of qualification'
PROFQUAL 'Achieved professional qualifications'
PRACTICE 'General practice ID'.

VALUE LABELS TVILLN TO OTHEINFO PROFQUAL INFOCONS 0 'no' 1 'yes' 8 'NA' 9 'NK'/USEFILLN USEFINFO PREFSOUR CONSPREF 1 'TV' 2 'Radio' 3 'Magazines' 4 'Newspapers' 5 'Journals' 6 'Books' 7 'Leaflets' 8 'Friends and relatives' 9 'Telephone advice line' 10 'Doctor' 11 'Nurse' 12 'Health visitor' 13 'Midwife' 14 'Pharmacist' 15 'Internet' 16 'Other' 98 'NA' 99 'NK'/NETACCES TO OTHEACCE 0 'no' 1 'yes' 8 'NA' 9 'NK'/TIMEUSED 1 'Less than 6 months' 2 '6 to 12 months' 3 '1-2 years' 4 '3 to 4 years' 5 '5 years or more'/EVERUSED TO NOTRUNET 0 'no' 1 'yes' 8 'NA' 9 'NK'/MINORIMP CAREMORE 1 '7' 2 '6' 3 '5' 4 '4' 5 '3' 6 '2' 7 '1' 9 'NK'/GENDER 1 'Male' 2 'female' 9 'NK'/EMPLOYMT 1 'employed' 2 'unemployed' 3 'retired' 4 'student' 5 'other' 9 'NK'/OCCUPATN 1 '1 Managers and senior officials' 2 '2 Professional occupations' 3 '3 Associate professional and technical occupations' 4 ' 4 Administrative and secretarial occupations' 5 ' 5 Skilled trades occupations' 6 ' 6 Personal service occupations' 7 '7 Sales and customer service occupations' 8 ' 8 Process, plant and machine operatives' 9 '9 Elementary occupations'/HIGHQUAL 0 'No qualifications' 1 'GCSE' 2

'GNVQNVQ' 3 'ALEVEL' 4 'FIRST DEGREE' 5 'HIGHDEGREE' 6 'OTHER QUALIFICATION' 9 'NK'/PROFQUAL 0 'No professional qualifications' 1 'teacher' 2 'medical doctor' 3 'dentist' 4 'nurse, midwife, health visitor' 5 'other professional' 8 'NA' 9 'NK'/PRACTICE 1 'Cardiff' 2 'Tylorstown'.

SAV OUTFILE ='N:\GCDOLAN\PhD\SPSS\SAV FILES\PATIENTSURVEY.SAV'.

APPENDIX 15

THE PROCESS OF IDENTIFYING THEMES AND SUB-THEMES

Stage 1		Stage 2 Merging themes		Stage 3 Compression of themes	
Themes	**Sub-themes**	**Themes**	**Sub-themes**	**Themes**	**Sub-themes**
Information sources	List of 16 information sources	**Approaches to information**	Passive approaches (*General information)* Active searching Triggers *Specific illness* *Responsibility for others* Internet searching	**Approaches to information**	Passive discovery Active Searching *Intermediary searching*
Information seeking behaviour	General information Specific-illness Responsibility for others Internet searching				
Information issues	Access Quantity Value Understanding Non-use of sources Internet trends Health information needs	**Internet issues**	Access Quantity Understanding Quality *(Value; Trust)* Internet trends	**Managing the internet**	Access Searching strategies Quantity Understanding Trust Internet trends
Use of information	Knowledge Contact others –GP New treatment/lifestyle Seek clarification Self diagnosis Discussion in consultations	**Information outcomes**	Knowledge New treatment/lifestyle Self-diagnosis Discussion in consultations *(Verification by GP)*	**Using health internet information**	Knowledge New treatment/lifestyle Self-diagnosis
Consultation issues	Challenge GP Time Opinion of GP Views about consulting Frequency of consultations Communication	**Consultation issues**	Challenge GP Time Opinion of GP Follow-up Views about consulting Frequency of consultations	**Patient-centred care**	Patient autonomy Consultation discourse Conflict Face-to-face contact
Patient issues	Patient characteristics Patient autonomy Decision making	**Patient autonomy**	Preparation Communication Decision making		

APPENDIX 16

ETHICAL APPROVAL

AWDURDOD IECHYD
BRO TAF
HEALTH AUTHORITY

20th June 2001 AD/CP/JJL

Ms G Dolan,
Research Assistant,
School of Care Sciences,
University of Glamorgan,
Pontypridd,
CF37 1DL.

Dear Ms Dolan,

01/4014 - Patients use of health information on the internet: is there evidence for a socio-economic divide

The Bro Taf Local Research Ethics Committee (Panel B) reviewed the above application for ethical approval at its meeting on the 20th June 2001. I am pleased to be able to inform you that ethical approval was granted subject to the following conditions:-

1. The Panel could see no reason for restricting this study to volunteers aged 75 and under, and requested a justification for excluding older patients.

2. The Panel was also unclear why patients with physical disabilities and patients who would need an escort into the surgery would be excluded. Members were of the view that it would be these very groups who would be more likely to use the internet for health information. The Panel would welcome your comments on this view.

3. Although not a condition of approval the Panel also required the information sheets to be placed on headed notepaper.

I confirm that the following documents were reviewed by Panel B at its meeting on the 20th June 2001:-

Patient Information Sheet (Questionnaire)	-	**1/May 2001**
Patient Information Sheet (Interview)	-	**2/May 2001**
Staff Information Sheet	-	**1/May 2001**
Patient Questionnaire	-	**no version/no date**

☐ HEADQUARTERS:
Churchill House
17 Churchill Way, Cardiff, CF10 2TW
PRIF SWYDDFA:
Tŷ Churchill
Ffordd Churchill, Caerdydd, CF10 2TW

☑ Temple of Peace and Health
Cathays Park, Cardiff, CF10 3NW
Teml Heddwch ac Iechyd:
Parc Cathays, Caerdydd, CF10 3NW

NHS CYMRU WALES

Tel: 029 20 402402 Fax/Ffacs: 029 20 402403 WHTN: 1809

I enclose for your information a copy of the Bro Taf Membership list on which the Members of Panel B, who were present at the meeting on the 20th June 2001, are indicated. I confirm that the Bro Taf Local Research Ethics Committee complies with the ICH Guidelines for Good Clinical Practice as they relate to an Independent Ethics Committee. A copy of the Committee's Constitution and Terms of Reference is available on request.

The committee attach certain standard conditions to all ethical approval. These are that if staff conducting research should change, any new staff should read the research programme submitted to the committee for ethical approval and this letter (and any subsequent letter I may write concerning this application for ethical approval); that if the procedures used in the research programme should change or the programme itself should be changed you should consider whether it is necessary to submit a further application for any modified or additional procedures to be approved and if the employment or departmental affiliation of the staff should change you should notify me of that fact. Any material changes to the structure or operation of the trial (including the recruitment of subjects) must be submitted to, and approved by, the Committee before being adopted. The Committee also ask that if any serious adverse events occur or if you should encounter any unexpected ethical issues, you will inform them of what these are. Full ethical approval needs to be resought if any study does not begin within two years of the date of this letter.

Yours sincerely,

A. Dowden.

Mrs A Dowden,
Chairman, Panel B,
Bro Taf Local Research Ethics Committee

APPENDIX 17

MULTIPLE LOGISTIC REGRESSION

Internet access

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	600.340[a]	.192	.259

a Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Classification Table[a]

Observed			Predicted		
			Do you have access to the Internet		Percentage Correct
			no	yes	
Step 1	Do you have access to the Internet	no	119	96	55.3
		yes	53	259	83.0
	Overall Percentage				71.7

a The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	practice	-.458	.252	3.297	1	.069	.633
	highqual	.117	.055	4.521	1	.033	1.124
	occupatn	-.258	.053	23.534	1	.000	.773
	age	-.039	.007	31.194	1	.000	.961
	Constant	3.520	.529	44.284	1	.000	33.772

a Variable(s) entered on step 1: practice, highqual, occupatn, age.

Variables in the Equation

		95.0% C.I.for EXP(B)	
		Lower	Upper
Step 1[a]	practice	.386	1.037
	highqual	1.009	1.252
	occupatn	.696	.857
	age	.948	.975
	Constant		

a Variable(s) entered on step 1: practice, highqual, occupatn, age.

Internet access (by practice)

Practice 1 (Affluent)

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	432.210[a]	.145	.201

a Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Classification Table[a]

Observed			Predicted		
			Do you have access to the Internet		Percentage Correct
			no	yes	
Step 1	Do you have access to the Internet	no	47	82	36.4
		yes	26	232	89.9
	Overall Percentage				72.1

a The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	age	-.032	.009	14.149	1	.000	.968
	employmt	-.297	.099	8.894	1	.003	.743
	occupatn	-.177	.069	6.644	1	.010	.837
	highqual	.141	.067	4.445	1	.035	1.151
	Constant	2.921	.570	26.289	1	.000	18.562

a Variable(s) entered on step 1: age, employmt, occupatn, highqual.

Variables in the Equation

		95.0% C.I.for EXP(B)	
		Lower	Upper
Step 1[a]	age	.952	.985
	employmt	.612	.903
	occupatn	.732	.958
	highqual	1.010	1.312
	Constant		

a Variable(s) entered on step 1: age, employmt, occupatn, highqual.

Practice 2 (Deprived)

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	155.592(a)	.195	.264

a Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Classification Table[a]

Observed			Predicted		
			Do you have access to the Internet		Percentage Correct
			no	yes	
Step 1	Do you have access to the Internet	no	68	17	80.0
		yes	27	27	50.0
	Overall Percentage				68.3

a The cut value is .500

Variables in the Equation - Deprived group

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	age	-.032	.015	4.410	1	.036	.968
	employmt	.014	.180	.006	1	.936	1.014
	occupatn	-.342	.088	15.205	1	.000	.710
	highqual	.149	.105	2.006	1	.157	1.161
	Constant	2.730	.966	7.982	1	.005	15.334

a Variable(s) entered on step 1: age, employmt, occupatn, highqual.

Variables in the Equation

		95.0% C.I.for EXP(B)	
		Lower	Upper
Step 1[a]	age	.940	.998
	employmt	.713	1.443
	occupatn	.598	.843
	highqual	.944	1.427
	Constant		

a Variable(s) entered on step 1: age, employmt, occupatn, highqual.

APPENDIX 18
FINAL INTERVIEW CODING

Final coding

Number of themes: 22

(1) Approaches to information seeking
(1.1) Passive discovery
(1.2) Active searching
(1.2.1) Intermediary searching
(2) Managing the internet
(2.1) Access
(2.1.1) Non-users of the internet
(2.2) Search strategies
(2.2.1) Proficiency
(2.3) Quantity of information
(2.4) Understanding
(2.5) Trust
(2.6) Internet trends
(3) Using health internet information
(3.1) Knowledge
(3.2) New treatment/lifestyle
(3.3) Self diagnosis
(4) Patient-centred care
(4.1) Patient autonomy
(4.2) Consultation discourse
(4.3) Conflict
(4.4) Face-to-face contact